



Experiences with General Practitioners expressed by families of children with intellectual disabilities: a qualitative study

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4 **Experiences with General Practitioners expressed by**
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7 **families of children with intellectual disabilities: a**
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10 **qualitative study**
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Abstract

Objective

To investigate parents' satisfaction, expectations and experiences with general practitioners follow up of children with ID and co-morbid behavioural and/or psychological problems.

Design

Qualitative study based on in-depth interviews with parents to children with ID and a broad range of accompanying health problems.

Setting

County centred study in Norway involving primary and specialist level of care.

Participants

Nine parents to a total of seven children with ID, all received services from an assigned GP and a specialist hospital department. Potentially participants was listed by a specialist hospital department, and strategically selected by the authors to represent a range of gender, diagnosis, location and assigned GPs.

Results

Three clusters of experiences emerged from the analysis; expectations, relations and actual use. The participants had low expectations to the GPs competence and involvement in their child, and they primarily used the GP for treatment of "simple" somatic problems. Regular GP consultations to check general or mental health, was only conducted in one child, and the interviewed group experienced that GPs neither had time nor was interested in behavioural and mental problems from every day living.

Conclusions

Families with ID children experience a complex health care system in situations where they are vulnerable to lack of information, involvement and competence. GPs represent a stable service system, and are in position to provide security, help and support for these families. Simple improvements as regular health checks, time, patience and involvement in every day behaviour problems, would enhance the satisfaction with the GPs.

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3 Article focus:
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- 6 • The aim of this study was to investigate parents' of children with intellectual
7 disabilities experiences with GPs, to locate important areas for improvement, and
8 propose fields for further exploration.
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12 Key messages:
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- 15 • This study shows that families with children with ID have low expectations to their
16 child's assigned GP, and the total health care needs are not met.
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 - 18 • GPs should provide regular health checks and have a broadminded attitude towards
19 the length of the consultation.
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 - 21 • When children with ID have co morbid challenging behaviour and/or mental health
22 problems, GPs seem to avoid bringing up these themes in the consultation.
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29 Strengths and limitations of this study:
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- 32 • Participants represented different diagnosis, challenges, gender and location (rural or
33 city).
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 - 35 • Findings are in line with a relative small number of similar studies on this field.
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 - 37 • Saturation of data was met early, so only a small group of participants are interviewed.
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Background

People with intellectual disabilities (ID) are at high risk of acquiring challenging behaviour and mental health problems [1-3], resulting in special health care needs. Some research indicates that health needs for people with ID are met improperly both in municipal and in specialist health care systems [4, 5]. A central role in general health care service is held by General Practitioners (GPs), as they are the first contact point when new health problems occurs, are closely connected to municipal services, the gatekeepers to specialist services and do much of the follow-up work. In addition GPs are the major prescriber for psychotropic medication to people with ID, mostly to treat “unrest” [6]. This study aimed to investigate parents’ satisfaction with GPs, to locate important areas for improvement, and propose fields for further exploration.

Several papers address the difficulties in providing health services for people with ID, especially when there are challenging behaviour and/or mental health problems [7-12]. The term challenging behaviour refers to any behaviour that puts the person displaying the behaviour and others at risk. This type of behaviour can interfere with home life and family members, and can affect the person’s ability to be able to safely interact with community members and facilities [13]. The term mental health problems are used in this article to include people with ID with and without a co morbid diagnosis. Mental health problems can be difficult to identify and diagnose in children with ID, which are indicated by a vast range of prevalence rate from 14 % - 60 % [2].

Organising health care services for people with ID has shifted from special institutions to community care [5]. Over the last 20 years, deinstitutionalisation of people with ID has been in progress in Norway, giving the municipalities responsibility for all health care services. The main objective for the deinstitutionalisation was to provide the same general services,

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3 rights and opportunities to people with ID as to the rest of the population [14]. Most children
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5 and adolescents with ID are living with their own biological family, some in foster care and in
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7 residents with other people with special needs, all with more or less help from general,
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9 municipal or special services.
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12 The Regular General Practitioner scheme (RGP) was implemented in Norway in 2001.
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14 Every citizen can choose their assigned GP, and it is possible to swap to another GP, even a
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16 GP in another municipality. Ideally the scheme creates a stable doctor-patient relationship, and is
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18 associated with reduced cost, improved health, and increased patient satisfaction. People in
19
20 Norway have the right to a personal GP, and in Norway less than a half percent chooses to
21
22 stand outside a RGP [15]. A system with a personal GP for everyone is in position to provide
23
24 personal services because the GP and their co-workers will know their patient, history and
25
26 family. A people-centred primary care that puts people first can reduce “rebound” visits for
27
28 unresolved health problems, improve job satisfaction for health care staff, and give the patient
29
30 a feeling of “being listened to” [16]. In a system where people with ID receive support,
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32 services and care from different service providers, GPs should represent a stable and equal
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34 service for everyone and be the coordinator of health services.
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41 It is a general goal in primary care and especially important for children with ID to reduce
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43 health disparities in the population. Despite this little knowledge or research about families’
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45 satisfaction with primary health care services exists. A study investigated primary health care
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47 received by families of children with ID, and demonstrated dissatisfaction with several
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49 aspects of health care services, including impact of their child’s condition on the family and
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51 ability to answer questions about the child’s condition [17]. Another study investigated the
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53 importance of physician knowledge of autism spectrum disorder, and showed that parents
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55 turned to other sources than physicians [18]. Both of these studies used surveys. Surveys are
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60 important to provide us with a representative and group based estimate of informants’

satisfaction. A qualitative study can help to develop hypothesis and may give more in-depth descriptions of content and challenges experienced. The aim of this study is thus to investigate parents' satisfaction with GPs, to locate important areas for improvement, and propose fields for further exploration.

Methods

A qualitative method

We chose a qualitative approach in order to obtain more precise descriptions of content in the challenges experienced by parents of children with ID. In depth interviews are well suited for inquiring of people's opinions and experiences, or searching for deeper understanding of opinions and attitudes to certain issues seen from the participants' perspective [19]. We preferred open interview to focus on participants' stories and perspectives on health services, in particular concerning GPs.

Participants

Data were drawn from seven interviews with a total of nine parents to young people (age 10 – 16) with ID and reported challenging behaviour and/or mental health problems. The sample reflected a variety in terms of experience and location (city and rural), diagnoses, age, gender, health service offers, challenging behaviour and mental health problems (Table 1).

Name	Age	Gender	Diagnose(s)	No. of informants	Location	Challenging behaviour	Psychopathological challenges
A	13	Female	Moderate ID Autism	1	City	Tantrums, ritualistic or repeated actions, screaming	Anxiety, panic attacks, OCD
B	15	Male	Moderate ID Autism	1	City	Occasional crying	None
C	14	Male	Mild ID Autism	1	Rural	Aggression, tantrums	Depression
D	16	Female	Mild ID	1	Rural	School refusal	Depression

E	13	Male	Mild ID ADHD	2	Rural	Aggression, suspicion, material damages	Paranoia, mania
F	10	Male	Mild ID Autism	1	City	Delay in falling asleep, refusal behaviour	Anxiety
G	10	Female	Mild ID ADHD	2	Rural	Aggression, controlling others	None

None of the families used the same GP. The participants were recruited after a staff meeting with habilitation services for children in Innlandet Hospital Trust, and included patients who currently receive services at Innlandet Hospital Trust, Hedmark Habilitation services. This service provides supervision to people with ID and their caregivers. The staff listed potential participants, and the researchers strategically selected participants with regard to location, diagnoses, age and gender. It was estimated that the sample size was likely to be 5-10 participants, e.g. until data saturation was reached and no new themes emerged. After 7 interviews the researchers found that no new themes were being generated, and we ended the recruiting of new participants.

Setting

Five interviews were conducted with the mother, while two interviews were conducted with both the father and the mother of the child. Participants could choose themselves to be interviewed at home or in a meeting room at the work place of the interviewers. Five interviews were conducted in the participant's home. The participants could stop the interview whenever they wanted with no further explanation. All participants were interviewed once and every interview session lasted for 60 to 90 minutes, with a mean of 70 minutes. Interviews were performed from August to October 2010 and all interviews were recorded on audio-files. The interviews were conducted by two of the authors (TF & KK), and consisted of largely open ended questions based on an interview guide in the form of keywords.

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2
3 The main questions asked in the interviews were:
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- 5 1. Can you tell us about your child?
- 6
- 7 2. Can you tell us about you, your child and your familys relation to the GP?
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10 **Analysis**

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12 Throughout the interview, the interviewers took note of participant's frequently used words
13 and phrases, statements that needed to be followed up and state of engagement, laughter,
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15 pauses and tones, all of which were used to analyze data. The interviews were transcribed for
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17 further analysis. The material was analyzed using systematic text condensation [19-21]. The
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19 first author read the transcript multiple times to get a comprehensive sense, identified
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21 meaningful units and transformed these into themes and subthemes capturing the "essential
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23 expressions". This was discussed among all the authors that independently commented and
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25 confirmed the appropriateness of coding, and provided additional and alternative ideas.
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31 The initial findings were presented at research meetings to offer more commentaries. The
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33 feedback was used to revise the final themes. For example, in these meetings, other
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35 researchers and general practitioners pointed out the relevance for this study, asked for
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37 additional information and gave us alternative interpretations of the material. Finally the first
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39 author drew a model to visualize themes and subthemes (Figure 1), and meaningful units were
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41 discriminated and categorised.
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45 The regional committee for medical research approved the study. Every participant signed
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47 an informed consent form.
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50 **Results**

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52 The parents of the seven young people with ID who were interviewed shared their
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54 experiences with health services and general practitioners. Parents told that their child had
55
56 several problems, and despite contact with specialist health services, they were still facing
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58 unsolved problems in every day living. The interviews revealed both challenging behaviour
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3 and mental health problems, e.g. depression, anxiety, tantrums, aggression and delay in falling
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5 asleep. Throughout the interview parents spoke about past events, contact with health
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7 services, every day living and family situation. The parents interviewed were eager to tell
8
9 their story, and the researchers found them enthusiastic and focused on problem solving.
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11 Several primary and specialist health services were involved in each child's situation.
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15 Three main categories with all together 13 subordinate themes emerged from the
16
17 descriptions of the parents of young children with ID when they were asked to describe the
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19 relation they and their child have to their GP. The idea of the model (see Figure 1) is to
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21 illustrate how the themes influence each other.
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30 Figure 1 approximately here
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36 **Expectations**

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38 The first main category epitomizes the expectations parents had to their child's GP (Table 2).
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40 The parents also described how they had selected the present GP, and also described changes
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42 in GPs attendance and continuity.
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46 Expectations

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49 GPs are treating simple somatic problems

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51 GPs are prescribing medication

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53 GPs are lacking knowledge in ID, challenging behaviour and mental health problems

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56 Parents expect no benefits in changing GP
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3 A common understanding contained expectations of the GP as one who prescribes
4 medication, and treats simple somatic problems. The parents did not expect the GP to treat
5 anything but somatic health problems, and a participant illustrated it like this:
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12 *“Actually he has mental problems...in general he is in good health” (C)*
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17 No one had searched for a GP with special competence with children with ID. All but one
18 had experienced involuntary change in GP, caused by GPs changing work place or continuing
19 education. The parents did not expect the GPs to be specialists in ID, challenging behaviour or
20 mental health problems, and had their reliance on hospital services. Even though it is easy to
21 change a GP in the RGP scheme, none of the participants interviewed had changed their
22 child’s GP. A mother said:
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34 *“I don’t know if it helps to change to another GP, and that’s why I haven’t done anything*
35 *about it” (F)*
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41 This participant used the same GP as her child, and was satisfied with the GP for her selves,
42 but not for her child.
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48 **Relations and experiences**

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50 The second main category epitomizes the contact and communication between the GP and the
51 family, through descriptions of meetings and contacts with the GP (Table 3).
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56 Relations and experiences

58 Lack of continuity and time
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Difficulty in adjusting to the role talking to a person with ID
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4 No regular follow up

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7 Lack of early involvement and interest

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10 The description of how often their child visited their GP varied on a range from never to
11 monthly. While one participant (C) saw no reason to visit the GP, another participant (E) went
12 to the doctor for simple treatment they could have done at home. Participant E did this to
13 strengthen the relation between her child and the GP, and to reduce her child's anxiousness in
14 visiting doctors.
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22 Participants' description of involuntary changes in GPs also brings up challenges when it
23 comes to GP/patient relation, medical history, family history and participant's trust in their
24 GP. There were also descriptions of earlier GPs with enthusiasm and interest in psychiatric
25 problems, but this was seen as extraordinary. Participants who have had such a GP missed
26 their earlier GP with these qualities. A participant said this about her child's first GP:
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"I trusted him more, and could talk with him about everything" (D)

Results show that a relation with a GP that opens for other issues than strictly medical or
somatic is needed, and this participant experienced a GP that really was interested in her and
her child, and opened for a relation that could meet her and her child's total health needs.

Participants also gave descriptions of the role their GP took when they were talking to
their child with ID. They experienced that GPs focused and looked at their child in the
consultation, and asked the following parent for more detailed descriptions. Some had
children with little or no vocal verbal skills, but regardless of this the GP was oriented against
their child. Even though this was a positive experience, the participant's also reported that
there was not time enough to get really deep in the complex situation. Participant G had

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3 solved this by always asking for extra time when they called for an appointment, and they
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5 described high satisfaction with their GP. Participant G said this when asked for health service
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7 satisfaction:
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12 *“Actually it’s the GP we are most satisfied with, except that he takes little initiative on his*
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14 *own” (G)*
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19 Participant G described a GP that listened to them and put into effect their proposals, but
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21 seldom or never suggested anything outside what was initiated by the parents.
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25 Another cluster of experiences dealt with regularity or existence of follow up
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27 consultations. There was one description of regular follow up, in this case annual
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29 consultation. A participant had never taken her child to their GP, and said:
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34 *“We are satisfied for our own sake, but for my child it has never really been an option to*
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36 *visit the GP” (A)*
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40 Participant A had a child with several challenges, and had been followed up by both
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42 habilitation services and paediatrics, but follow up from paediatrics was ended few months
43
44 ago. Nevertheless the GP was responsible for prescription of psychotropic medication to treat
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46 panic disorder and anxiety. In this special case the GP had called a paediatric physician for
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48 advice. The paediatric physician had then called a specialist department for ID and psychiatric
49
50 co morbidity, and the conclusion had been that the child was to be given psychotropic
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52 medication, although none of the doctors actually had seen the child. Participant C had also
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54 been prescribed medication by phone, and said:
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3 *“His GP has prescribed sleeping medicine once, and I recall that’s the only time his GP*
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5 *had to deal with him. And then he didn’t need to show up.”*
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10 The fact that medication was given to acute or more permanent problems, and that GPs did
11 not find it necessary to see the child or do any on-site examination are reported. The GP has to
12 rely exclusively on their own interpretations of what the parents or others say, in combination
13 with patient journal and possible earlier examinations. In addition none of the parents were
14 given instructions on how to evaluate the possible effect of the medication.
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24 **Actual use and outcome**

25 The third and last main category epitomizes descriptions of how the participants use their GP
26 (Table 4).
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31 Actual use and outcome

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35 Families use GP for prescriptions and somatic problems

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37 Participants’ do not involve GPs in challenging behaviour and mental health problems

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39 Participants’ experiences lack of GP participation in collaborative group meetings
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44 The kind of expectation and relation the participant’s have to their GP were expressed by
45 somatic focus in consultations and lack of involvement. Each child had services from several
46 primary and specialist health services, and the parents were in some matter disoriented about
47 were to seek help for their child’s specific challenges.
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53 A cluster of descriptions deals with the situation that GPs ends up being a doctor for
54 simple somatic problems and prescriptions, and are not involved in behavioural issues or
55 mental health problems of their child. A participant said this when asked why they don’t use
56 their GP for challenging behaviour or mental health problems:
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“I think...first of all my GP is sceptic about it, and I think it’s to special for them” (A)

Results show the expectation that GPs can’t deal with challenging behaviour and mental health problems, and describes parents that did not involve their GP in the total situation regarding their child.

A subtheme is GP participation and involvement in collaborative groups and group meetings. When several health services are involved, collaborative group meetings are carried out to coordinate services to better meet the need of the patient. Participants reported lack of GP participation in collaborative group meetings. Two scenarios were revealed in the interviews: i. GPs were invited to collaborative group meetings, but did not show up. ii. GPs were not expected to contribute in a collaborative group meeting, and were by that not invited.

A participant said this at the end of the interview when we asked if they would involve their GP in collaborative group meetings:

“Yes, it is actually a new dimension we haven’t thought of before.” (G)

This illustrates the need for information about the possibilities and benefits families with an ID child can achieve by involving their GP in collaborative group meetings. It also illustrates the bi-directionality of an interview setting, showing that participants and interviewers share information, and influence each other.

Discussion

The main findings from this study are that parents have low expectations to their GP and accept low frequency of contact and the fact that the GP is focused on somatic and medical issues.

The children of all participants received services from the habilitation department in their local hospital. The satisfaction with habilitation services was, however, not optimal, and the total health care need was not met. Several municipal and special health care services were involved with every child, bringing up the need for co-ordinated services. GPs represent a stable service, and are in position to provide these families with a consistent collaborative partner with close contact to other health care services. Results from this study suggest that GPs do not take this coordinating role for this patient group. The participants experienced low or no attendance from GPs in collaborative group meetings, and ended up being the ultimate coordinators themselves. The fact that none of the participants had present GPs, who participated or was involved in group meetings, strengthens the impression that GPs are left to deal with simple problems. This can result in lack of involvement and that GPs competence and knowledge about health services are not fully exploited.

Regular GP health checks might give the GP the necessary tool to a successful consultation; a good relation to the child. Several areas of concern are identified in children with ID. Nutrition, constipation, epilepsy, thyroid disease, medication, physical activity, challenging behaviour and mental health problems, needs attention and be checked on regular basis. Regular follow up is also suited to make sure that the patient actually meets the GP, and can provide a feeling of security between the GP, the child with ID and his/hers family. This may contribute to the parents feeling of security, may prevent health problems in the child, but also prevent health problems in these families. The families need to trust their GP to feel secure, so they can call or visit their GP when it is necessary. In some cases the GP has to be

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3 patient, let go with his white coat, and slowly approach to make the child feel secure.

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5 Sometimes a GP will have to repeat this procedure several times before they can touch the
6
7 child, make it co operative and take blood samples or do other necessary examinations.
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10 One participant always asked for extra time when they asked for a GP appointment, and
11 they were in general satisfied with their GP, even though they reported that they told him
12 what to do. This illustrates satisfaction with their GP despite lack of initiative. Little
13 knowledge or research about families' satisfaction with primary health care services exists,
14 but some surveys have shown similar results as our qualitative study [17;18]. Despite the fact
15 that specialist services are involved, GPs competence and involvement in ID are expected and
16 wanted. An important issue for further research is to address the content of the medical school
17 regarding ID, challenging behaviour and mental health problems. Parents seem to turn to
18 other sources than GPs for information, but are at the same time disoriented about where to
19 seek help. It is also important to look at the shared responsibility of the habilitation services
20 and the GPs. It might be that one of the reasons for lack of involvement among GPs is that
21 they are "afraid to step on specialist's toes".
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38 Focus also needs to be pointed at the GPs that prescribed medication without on-site
39 examination. Interpretations of verbal information are a necessary component, especial when
40 the patient have troubles or completely lack adequate communication skills. Information from
41 people who knows the children is naturally given closely attention, but can't fully compensate
42 for the GPs own observation by hands, eyes and ears. As a mainstream service GPs need
43 broad competence, and it can be difficult to acquire knowledge about minority groups like
44 people with ID, in special when they have behavioural and psychopathological challenges.
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The existing major classification systems, DSM-IV-TR and ICD-10, are difficult to apply and
diagnosing requires specialist multi professional involvement [10, 22]. Especially when it
comes to challenging behaviour and mental health problems among people with ID, the

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3 specialist's advices will differ, and there exists no national guidelines. This complexity may
4
5 be a reason for why GPs avoid bringing up psychopathological or behavioural issues, or
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7 avoids involvement when this topic is mentioned.
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10 **Limitations and relevance**

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12 Everyone in the research group read transcription of the completed interviews, and when
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14 seven interviews were finished, the researchers agreed that we had met a saturation of data.
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16 Reasons for saturation of data could rely on the fact that the participants represented a
17
18 relatively homogenous group. They were all from the same county, represented a low range of
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20 age (10-16), received health services from habilitation services for children, and were
21
22 recruited because they had reported challenging behaviour and/or mental health problems.
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24 This is obvious threats to external validity, and limits the immediate generalisation of the
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26 results. Nevertheless the participants represented different diagnosis, challenges, gender and
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28 location (rural or city), and is consistent with international research that points out difficulties
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30 experienced by families, and problems with general health care for people with ID [17, 18, 23,
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32 24]. By this our findings can have transferability and importance for further research in the
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34 field.
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42 **Conclusion**

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45 This study shows that GPs are inadequately used by families with children with ID. In
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47 addition several health care providers are involved in every focused child, but the total health
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49 care needs are not met by these families. The attention needs to be focused at GPs
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51 involvement in issues like preventive screening services for somatic health, participation in
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53 collaborative meetings and involvement in challenging behaviour and mental health problems.
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57 In general, the families investigated in this study have low expectations to their GPs, and
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59 seldom involve their personal GP in major issues like challenging behaviour and mental
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health problems. And when GPs are involved, it seems to be a temporary contribution,

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3 although problems seem to continue for the families and their child. One explanation of little
4 involvement by GPs can be that paediatric department habilitation services make available
5 these services, and by that give the GPs an impression that health care needs are met. GPs
6 have close connection to municipal services and are gate-keepers of specialist health services,
7 but this potential was not fully exploited by the participant's we interviewed. Properly used,
8 the GP has potential to be a greater support for families with need for complex health services
9 for their child.
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20 Further research is needed to investigate factors that could influence on GPs follow up of
21 children with ID, and this paper addresses some issues that need to be focused in such
22 research. Little have been done to study how GPs interact with children with ID, and their
23 caregivers, and this study can pinpoint some important issues related to this field. To sum up,
24 the recommendations from the families involved is: i. regular GP health checks, ii. GPs
25 should have a broadminded attitude towards the length of the consultation, iii. GPs should be
26 interested in every day living including the situation of the parents.
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Competing interests

The authors declare that they have no competing instructions.

Authors' contributions

TF conducted the interviews, transcribed and analyzed them. He also wrote the paper. ORH and LJD analyzed interviews. KK participated in the interviews and analyzed them. LL supervised the overall project. All authors have read and approved the final manuscript.

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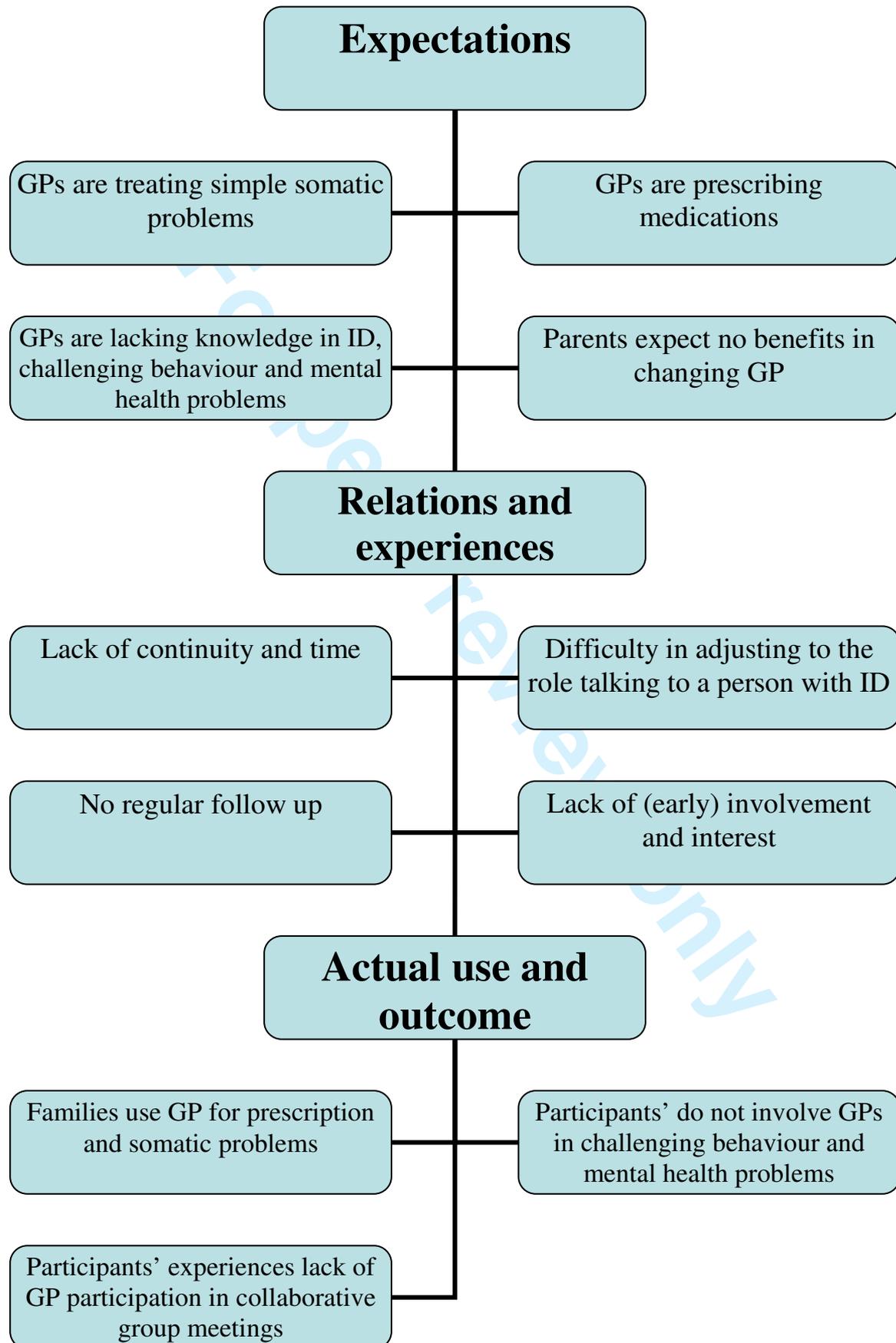
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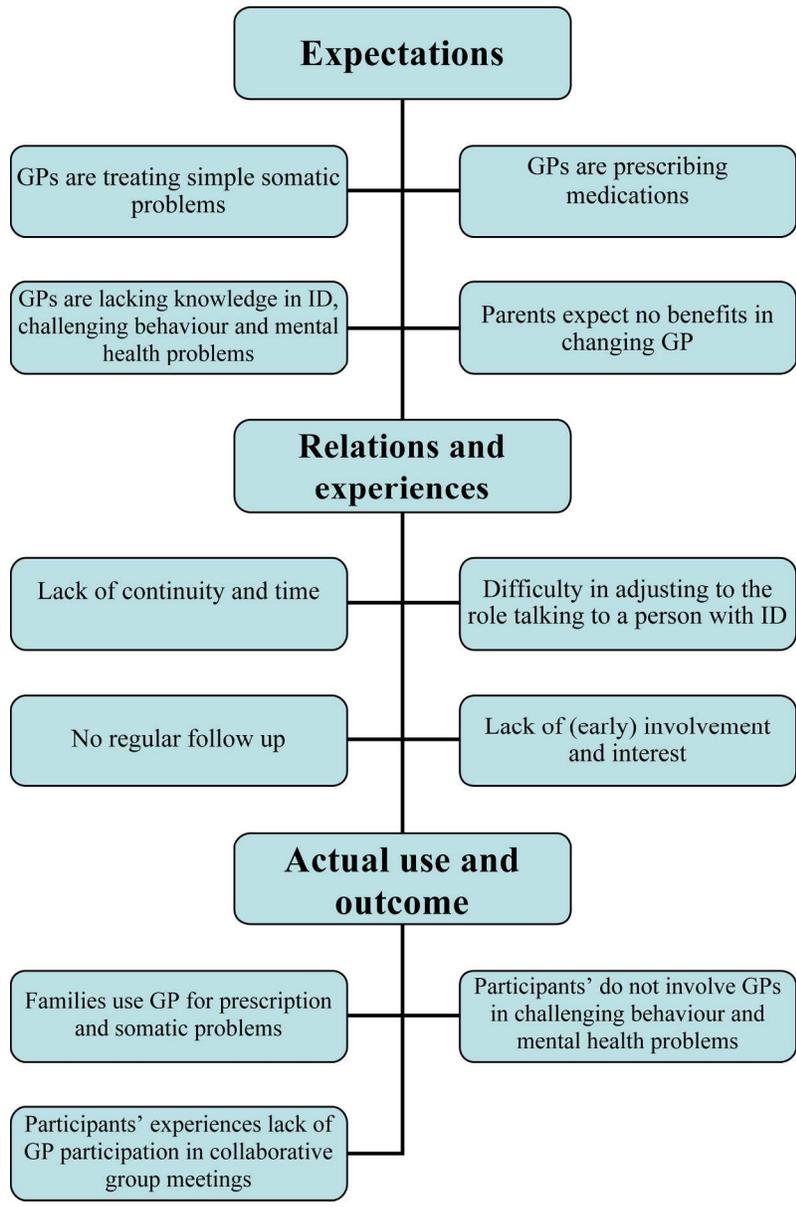
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For peer review only

FIGURE 1 *Model with themes and subthemes*



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160x232mm (300 x 300 DPI)

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3 No Item Guide questions/description
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5 Domain 1: Research team and reflexivity
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8 Personal Characteristics

- 9 1. Interviewer/facilitator: Which author/s conducted the interview or focus group?
10 2. Credentials: What were the researcher's credentials? E.g. PhD, MD
11 3. Occupation: What was their occupation at the time of the study?
12 4. Gender: Was the researcher male or female?
13 5. Experience and training: What experience or training did the researcher have?
14
15
16 Relationship with participants
17 6. Relationship established: Was a relationship established prior to study commencement?
18 7. Participant knowledge of the interviewer: What did the participants know about the researcher? e.g. personal goals, reasons for doing
19 the research
20 8. Interviewer characteristics: What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions,
21 reasons and interests in the research topic
22
23

24 Domain 2: study design

25 Theoretical framework

- 26 9. Methodological orientation and Theory: What methodological orientation was stated to underpin the study? e.g. grounded theory,
27 discourse analysis, ethnography, phenomenology, content analysis
28
29

30 Participant selection

- 31 10. Sampling: How were participants selected? e.g. purposive, convenience, consecutive, snowball
32 11. Method of approach: How were participants approached? e.g. face-to-face, telephone, mail, email
33 12. Sample size: How many participants were in the study?
34 13. Non-participation: How many people refused to participate or dropped out? Reasons?
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37 Setting

- 38 14. Setting of data collection: Where was the data collected? e.g. home, clinic, workplace
39 15. Presence of non-participants: Was anyone else present besides the participants and researchers?
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3 16. Description of sample: What are the important characteristics of the sample? e.g. demographic data, date
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6 Data collection

7 17. Interview guide: Were questions, prompts, guides provided by the authors? Was it pilot tested?

8 18. Repeat interviews: Were repeat interviews carried out? If yes, how many?

9 19. Audio/visual recording: Did the research use audio or visual recording to collect the data?

10 20. Field notes: Were field notes made during and/or after the interview or focus group?

11 21. Duration: What was the duration of the interviews or focus group?

12 22. Data saturation: Was data saturation discussed?

13 23. Transcripts returned: Were transcripts returned to participants for comment and/or correction?
14
15

16 Domain 3: analysis and findings

17 Data analysis

18 24. Number of data coders: How many data coders coded the data?

19 25. Description of the coding tree: Did authors provide a description of the coding tree?

20 26. Derivation of themes: Were themes identified in advance or derived from the data?

21 27. Software: What software, if applicable, was used to manage the data?

22 28. Participant checking: Did participants provide feedback on the findings?
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26 Reporting

27 29. Quotations presented: Were participant quotations presented to illustrate the themes / findings? Was each
28 quotation identified? e.g. participant number

29 30. Data and findings consistent: Was there consistency between the data presented and the findings?

30 31. Clarity of major themes: Were major themes clearly presented in the findings?

31 32. Clarity of minor themes: Is there a description of diverse cases or discussion of minor themes?
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Experiences with General Practitioners expressed by families of children with intellectual disabilities and challenging behaviour: a qualitative study

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Experiences with General Practitioners expressed by families of children with intellectual disabilities and challenging behaviour: a qualitative study

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Words: 3963

ABSTRACT

Objective

To investigate parents' experiences with general practitioners (GPs) follow up of children with [intellectual disabilities \(ID\)](#) and co-morbid behavioural and/or psychological problems.

Design

Qualitative study based on in-depth interviews with parents to children with ID and a broad range of accompanying health problems.

Setting

County centred study in Norway involving primary and specialist level of care.

Participants

Nine parents to a total of seven children with ID, all received services from an assigned GP and a specialist hospital department. Potentially participants [were](#) listed by a specialist hospital department, and strategically selected by the authors to represent a range of gender, diagnosis, location and assigned GPs.

Results

Three clusters of experiences emerged from the analysis; expectations, relations and actual use. The participants had low expectations to the GPs competence and involvement in their child, and they primarily used the GP for treatment of "simple" somatic problems. Regular GP consultation to check general or mental [health](#) was only conducted in one [child](#). [The participants](#) experienced that GPs neither had time nor [were](#) interested in behavioural and mental problems [among these children](#).

Conclusions

Families with ID children experience a complex health care system in situations where they are vulnerable to lack of information, involvement and competence. GPs represent a stable service system, and are in position to provide security, help and support for these families. [Parents' experiences could be improved by](#) regular health checks, time, patience and [interest by GPs in challenging behaviour](#).

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3 Article focus:
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- 6 • The aim of this study was to investigate parents' of children with intellectual
7 disabilities experiences with GPs, to locate important areas for improvement, and
8 propose fields for further exploration.
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12 Key messages:
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- 15 • This study shows that families with children with ID have low expectations to their
16 child's assigned GP, and the total health care needs are not met.
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- 19 • GPs should provide regular health checks and have a broadminded attitude towards
20 the length of the consultation.
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- 23 • When children with ID have co morbid challenging behaviour and/or mental health
24 problems, GPs seem to avoid bringing up these themes in the consultation.
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30 Strengths and limitations of this study:
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- 32 • Participants represented different diagnosis, challenges, gender and location (rural or
33 city).
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- 36 • Findings are in line with a relative small number of similar studies on this field.
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- 39 • Saturation of data was met early, so only a small group of participants are interviewed.
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BACKGROUND

People with intellectual disabilities (ID) are at high risk of acquiring challenging behaviour and mental health problems [1-3], resulting in special health care needs. Some research indicates that health needs for people with ID are not properly met neither in municipal nor in specialist health care systems [4;5]. A central role in general health care service is held by general practitioners (GPs), as they are the first contact point when new health problems occurs, are closely connected to municipal services, the gatekeepers to specialist services and do much of the follow-up work. In addition GPs are the major prescriber for psychotropic medication to people with ID, mostly to treat “unrest” [6].

Several papers address the difficulties in providing health services for people with ID, specially when there are challenging behaviour and/or mental health problems [7-12]. The term challenging behaviour refers to any behaviour that puts the person displaying the behaviour and others at risk. This type of behaviour can interfere with home life and family members, and can affect the person’s ability to safely interact with community members and facilities [13]. Mental health problems can be difficult to identify and diagnose in children with ID, which are indicated by a vast range of prevalence rates from 14 % - 60 % [2]. The term mental health problems are used in this article to include all symptoms of co morbid psychiatric disorder like depression and anxiety.

Unmet physical healthcare needs is also reported among people with ID [14-16]. A study demonstrated concomitantly more disease detection after intervention of a health assessment programme [17], and another study demonstrated benefits in health outcomes after intervention with a health screening programme [18]. A vulnerable group among people with ID is people with mental health problems. It may be appropriate to include challenging behaviour because there is suggested a considerable overlap between mental health problems

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3 and challenging behaviour [19;20]. This group is vulnerable because of the common interface
4 between mental health problems and medical illness. Psychotropic medication can give
5 physical side effects, physical problems can be expressed in challenging behaviour or mental
6 health problems and social factors like unhealthy lifestyle and poor living environment can
7 contribute to physical problems [21]. Even though this is a challenge that includes several
8 health service providers, GPs often have a long-term perspective and geographical closeness
9 that puts them in a special position. GPs responsibility for this vulnerable and “hard to hear”
10 group are not clear, but should involve regular health checks and collaboration with other
11 health services.
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25 The Regular General Practitioner scheme (RGP) was implemented in Norway in 2001.
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27 Every citizen can choose their assigned GP, and it is possible to swap to another GP, even a
28 GP in another municipality. In Norway less than half percent choose to stand outside a RGP
29 [22]. A system with a personal GP for everyone is in position to provide personal services
30 because the GP and their co-workers will know their patient, history and family. A people-
31 centred primary care that puts people first can reduce “rebound” visits for unresolved health
32 problems, improve job satisfaction for health care staff, and give the patient a feeling of
33 “being listened to” [23].
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43 It is a general goal in primary care and especially important for children with ID to reduce
44 health disparities in the population. Despite this little knowledge or research about families’
45 experiences with primary health care services exists. A study investigated primary health care
46 received by families of children with ID, and demonstrated dissatisfaction with several
47 aspects of health care services, including impact of their child’s condition on the family and
48 ability to answer questions about the child’s condition [24]. Surveys are important to provide
49 us with a representative and group based estimate of informants’ satisfaction. A qualitative
50 study can give more in-depth descriptions of content and challenges experienced and by this
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[help to develop hypothesis](#). The aim of this study is thus to investigate parents' [experiences](#) with GPs, to locate important areas for improvement, and propose fields for further exploration.

METHODS

A qualitative method

We chose a qualitative approach in order to obtain more precise descriptions of content in the challenges experienced by parents of children with ID. In depth interviews are well suited for inquiring people's opinions and experiences, or searching for deeper understanding of opinions and attitudes to certain issues seen from the participants' perspective [25]. We preferred open interview to focus on participants' stories and perspectives on health services, in particular concerning GPs.

Participants

Data were drawn from seven interviews with a total of nine parents to young people (age 10 – 16) with ID and reported challenging behaviour and/or mental health problems ([see table 1](#)). The sample reflected a variety in terms of experience and location (city and rural), [level of ID](#), age, gender [and](#) health service offers.

TABLE 1 *Participants (Young people with Intellectual Disability) name, challenging behaviour, mental health problem and service providers beside GPs and habilitation services.*

Name	Challenging behaviour	Mental health problem	Present service providers besides GPs and Habilitation Services
A	Tantrums, ritualistic or repeated actions, screaming	Anxiety, panic attacks, OCD	Paediatric hospital clinic, orthopaedic hospital clinic, national epilepsy center, pedagogical and psychological services, auxiliary housing, health visitor, physiotherapist
B	Occasional crying	None	Auxiliary housing, pedagogical and psychological services, support person, community activity services, health visitor
C	Aggression, tantrums	Depression	Pedagogical and psychological services, support person, health visitor, community

			<u>care services</u>
<u>D</u>	<u>School refusal</u>	<u>Depression</u>	<u>Child and youth psychiatric hospital services, health visitor, pedagogical and psychological services</u>
<u>E</u>	<u>Aggression, suspicion, material damages</u>	<u>Paranoia, mania</u>	<u>Paediatric hospital clinic, community coordination services, auxiliary housing, support person, pedagogical and psychological services, child welfare</u>
<u>F</u>	<u>Delay in falling asleep, refusal behaviour</u>	<u>Anxiety</u>	<u>Paediatric hospital clinic, child and youth psychiatric hospital services, community coordination services, pedagogical and psychological services, support person, auxiliary housing, physiotherapist, ergonomist</u>
<u>G</u>	<u>Aggression, controlling others</u>	<u>None</u>	<u>Pedagogical and psychological services, physiotherapist, community care services, health visitor, speech therapist</u>

None of the families used the same GP. The participants were recruited after a staff meeting with habilitation services for children at Innlandet Hospital Trust, and included patients who currently received services at Innlandet Hospital Trust, Hedmark Habilitation services. This service provides supervision to approximately 450 people with ID and their caregivers. The staff listed 14 potential participants with reported challenging behaviour and/or mental health problems, and the researchers strategically selected participants with regard to location, diagnoses, age and gender. It was estimated that the sample size was likely to be 5-10 participants, e.g. until data saturation was reached and no new themes emerged. After 7 interviews the researchers found that no new themes were being generated, and we terminated the recruiting of new participants.

Setting

Five interviews were conducted with the mother, while two interviews were conducted with both the father and the mother of the child. Participants could choose themselves to be interviewed at home or in a meeting room at the work place of the interviewers. Five interviews were conducted in the participant's home. The participants could stop the interview whenever they wanted with no further explanation, but no one did. All participants were

1
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3 interviewed once and every interview session lasted for 60 to 90 minutes, with a mean of 70
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5 minutes. Interviews were performed from August to October 2010 and all interviews were
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7 recorded on audio-files. The interviews were conducted by two of the authors (TF & KK), and
8
9 consisted of largely open ended questions based on an interview guide in the form of [main](#)
10
11 [questions and a checklist](#).
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13

14
15 The main questions asked in the interviews were:

- 16
17 1. Can you tell us about your child?
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19 2. Can you tell us about you, your child and your [family's](#) relation to the GP?

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21 [The checklist was used to gather information that was otherwise not told, or to deepen](#)
22
23 [incomplete information. Typical follow up questions were related to type of challenging](#)
24
25 [behaviour, service offers from primary healthcare services and secondary healthcare](#)
26
27 [specialities, mental health problems, health check routines and frequency of contact with the](#)
28
29 [GP](#).
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33 34 **Analysis**

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36 Throughout the interview, the interviewers took note of participant's frequently used words
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38 and phrases, statements that needed to be followed up and state of engagement, laughter,
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40 pauses and tones, all of which were used to analyze data. The interviews were transcribed for
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42 further analysis. The material was analyzed using systematic text condensation [\[25-27\]](#). The
43
44 first author read the transcript multiple times to get a comprehensive sense, identified
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46 meaningful units and transformed these into themes and subthemes capturing the "essential
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48 expressions". This was discussed among all the authors that independently commented and
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50 confirmed the appropriateness of coding, and provided additional and alternative ideas.
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54 The initial findings were presented at research meetings to offer more commentaries. The
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56 feedback was used to revise the final themes. For example, in these meetings, other
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58 researchers and general practitioners pointed out the relevance for this study, asked for
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3 additional information and gave us alternative interpretations of the material. Finally the first
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5 author drew a model to visualize themes and subthemes (Figure 1), and meaningful units were
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7 discriminated and categorised.
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10 The regional committee for medical research approved the study. Every participant signed
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12 an informed consent form.
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15 16 RESULTS

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19 Throughout the interview parents spoke about past events, contact with health services, every
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21 day living and family situation. The parents interviewed were eager and enthusiastic about
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23 telling their story. The interviews revealed both challenging behaviour and mental health
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25 problems, e.g. depression, anxiety, tantrums, aggression and delay in falling asleep. Despite
26
27 contact with several primary and specialist health services, the families were still facing
28
29 unmet health needs. Typically primary health services in addition to the assigned GP were
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31 pedagogical and psychological services, child welfare services, individual coordinators and
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33 auxiliary housing. In addition to habilitation services, other specialist services involved were
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35 typically psychiatric services for children and adolescents and paediatric hospital services (for
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37 more details see table 1).
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43 Three main categories with all together 13 subordinate themes emerged from the
44
45 descriptions of the parents of young children with ID when they were asked to describe the
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47 relation they and their child had to their GP. The idea of the model (see Figure 1) is to
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49 illustrate how the themes influence each other.
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57 Figure 1 approximately here
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Expectations

The first main category epitomizes the expectations parents had to their child's GP. The parents also described how they had selected the present GP, and also described changes in GPs attendance and continuity.

A common understanding contained expectations of the GP as one who prescribes medication, and treats simple somatic problems. The parents did not expect the GP to treat anything but somatic health problems, and a participant illustrated it like this:

“Actually he has mental problems...in general he is in good health”

No one had searched for a GP with special competence with children with ID. All but one had experienced involuntary change of GP, caused by GPs changing work place or continuing education. The parents did not expect the GPs to be specialists in ID, challenging behaviour or mental health problems, and had their reliance on hospital services. Even though it is easy to change a GP, none of the participants interviewed had changed their child's GP. A mother said:

“I don't know if it helps to change to another GP, and that's why I haven't done anything about it”

This participant used the same GP as her child, and was satisfied with the GP for herself, but not for her child.

Relations and experiences

The second main category epitomizes the contact and communication between the GP and the family, through descriptions of meetings and contacts with the GP. The description of how

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3 often their child visited their GP varied on a range from never to monthly. One participant
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5 saw no reason to take the child to the GP, and explained that the GP never had asked about it.
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8 Another participant went to the doctor for simple treatment they could have done at home. An
9
10 explanation for frequent appointments was to strengthen the relation between the child and the
11
12 GP, and to reduce the child's anxiousness in visiting doctors. There were no descriptions of
13
14 regular health checks, primary care-based health reviews or more frequent appointments
15
16 initiated by the GP.
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20 Participants' description of involuntary changes in GPs also brings up challenges when it
21
22 comes to GP/patient relation, medical history, family history and participant's trust in their
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24 GP. There were also descriptions of earlier GPs with enthusiasm and interest in psychiatric
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26 problems, but this was seen as extraordinary. Participants who have had such a GP missed
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28 their earlier GP with these qualities. A participant said this about her child's first GP:
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34 *"I trusted him more, and could talk with him about everything"*
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39 The interviews show that a relation with a GP that opens for other issues than strictly medical
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41 or somatic is needed, and the participant above experienced a GP that really was interested in
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43 her and her child, and opened for a relation that could meet her and her child's total health
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45 needs.
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48
49 Participants also gave descriptions of the role their GP took when they were talking to
50
51 their child with ID. They experienced that GPs focused and looked at their child in the
52
53 consultation, and asked the following parent for more detailed descriptions. Some had
54
55 children with little or no vocal verbal skills, but regardless of this the GP was oriented against
56
57 their child. Even though this was a positive experience, the participant's also reported that
58
59 there was not time enough to get really deep in the complex situation. One participant had
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1
2
3 solved this by always asking for extra time when they called for an appointment, and they
4
5 described good experiences with their GP:
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9
10 *“Actually it’s the GP we are most satisfied with, except that he takes little initiative on his*
11
12 *own”*
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16
17 This participant described a GP that listened to them and put into effect their proposals, but
18
19 seldom or never suggested anything outside what was initiated by the parents.
20
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22 Another cluster of experiences dealt with regularity or existence of follow up
23
24 consultations. There was one description of regular follow up, in this case annual
25
26 consultation. A participant had never taken her child to their GP, and said:
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31 *“We are satisfied for our own sake, but for my child it has never really been an option to*
32
33 *visit the GP”*
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36
37
38 This participant had a child with several challenges, and had been followed up by both
39
40 habilitation services and paediatrics, but follow up from paediatrics was ended few months
41
42 ago. Nevertheless the GP was responsible for prescription of psychotropic medication to treat
43
44 panic disorder and anxiety. In this special case the GP had called a paediatric physician for
45
46 advice. The paediatric physician had then called a specialist department for ID and psychiatric
47
48 co morbidity, and the conclusion had been that the child was to be given psychotropic
49
50 medication, although none of the doctors actually had seen the child. Another participant had
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54
55 also been prescribed medication by phone, and said:
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3 *“His GP has prescribed sleeping medicine once, and I recall that’s the only time his GP*
4
5 *had to deal with him. And then he didn’t need to show up.”*
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9

10 The fact that medication was given to acute or more permanent problems, and that GPs did
11 not find it necessary to see the child or do any on-site examination are reported. The GP has to
12 rely exclusively on their own interpretations of what the parents or others say, in combination
13 with patient journal and possible earlier examinations. In addition none of the parents were
14 given instructions on how to evaluate the possible effect of the medication.
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24 **Actual use and outcome**

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26 The third and last main category epitomizes descriptions of how the participants use their GP.
27 The kind of expectation and relation the participant’s have to their GP were expressed by
28 somatic focus in consultations and lack of involvement. Each child had services from several
29 primary and specialist health services, and the parents were in some matter disoriented about
30 were to seek help for their child’s specific challenges.
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38 A cluster of descriptions deals with the situation that GPs end up being a doctor for simple
39 somatic problems and prescriptions, and are not involved in behavioural issues or mental
40 health problems of their child. A participant said this when asked why they don’t use their GP
41 for challenging behaviour or mental health problems:
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50 *“I think...first of all my GP is sceptic about it, and I think it’s to special for them”*
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55 Parents’ expectation is that GPs can’t deal with challenging behaviour and mental health
56 problems, and describe that they did not involve their GP in the total situation regarding their
57 child.
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1
2
3 A subtheme is GP participation and involvement in collaborative groups and group
4 meetings. When several health services are involved, collaborative group meetings are carried
5 out to coordinate services to better meet the need of the patient. Participants reported lack of
6 GP participation in collaborative group meetings. Two scenarios were revealed in the
7 interviews: i. GPs were invited to collaborative group meetings, but did not show up. ii. GPs
8 were not expected to contribute in a collaborative group meeting, and were by that not invited.
9
10 A participant said this at the end of the interview when we asked if they would involve their
11 GP in collaborative group meetings:
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“Yes, it is actually a new dimension we haven’t thought of before.”

This illustrates the need for information about the possibilities and benefits families with an
ID child might achieve by involving their GP in collaborative group meetings. It also
illustrates the bi-directionality of an interview setting, showing that participants and
interviewers share information, and influence each other.

DISCUSSION

The main findings from this study are that parents have low expectations to their GP,
accept low frequency of contact and feel that the GP is focused on somatic and medical
issues. The families use their child’s GP for prescriptions and “simple” somatic problems, but
they do not involve them in challenging behaviour or mental health problems. In addition the
parents experienced lack of GP participation in collaborative group meetings. None of the
parents however wanted to change their child’s assigned GP.

GPs represent a stable service, and are in position to provide these families with a
consistent collaborative partner with close contact to other health care services. Results from

1
2
3 | this study give rise to the suggestion that GPs do not take this coordinating role for this
4
5 patient group. The participants experienced low or no attendance from GPs in collaborative
6
7 group meetings, and ended up being the ultimate coordinators themselves. The fact that none
8
9 of the participants had present GPs, who participated or were involved in group meetings,
10
11 strengthens the impression that GPs are left to deal with simple problems. This can result in
12
13 lack of involvement and that GPs competence and knowledge about health services are not
14
15 fully exploited. This may lead to the assumption that low expectations from the parents,
16
17 results in reduced health services from the GP.

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22 General practice based health assessment programmes for people with ID have
23
24 demonstrated benefits related to identification of health needs, meeting health needs and
25
26 reducing health inequalities [17;18]. Regular GP health checks might give the GP the
27
28 necessary tool to a successful consultation; a good relation to the child. Several areas of
29
30 concern are identified in children with ID. Nutrition, constipation, epilepsy, thyroid disease,
31
32 medication, physical activity, challenging behaviour and mental health problems, needs
33
34 attention and be checked on regular basis. Regular follow up is also suited to make sure that
35
36 the patient actually meets the GP, and can provide a feeling of security between the GP, the
37
38 child with ID and his/hers family. This may contribute to the parents feeling of security, may
39
40 prevent health problems in the child, but also prevent health problems in these families. The
41
42 families need to trust their GP to feel secure, so they can call or visit their GP when it is
43
44 necessary. The parents interviewed did not expect their GP to be involved in their child's total
45
46 health needs as long as issues like challenging behaviour and mental health problems was
47
48 avoided in GP consultations.

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55 One participant always asked for extra time when they asked for a GP appointment, and
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57 they were in general satisfied with their GP, even though they reported that they told him
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59 what to do. This illustrates satisfaction with their GP despite lack of initiative. Little
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3 knowledge or research about families' satisfaction with primary health care services exists,
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5 but some surveys have shown similar results as our qualitative study [24;28]. An important
6
7 issue for further research is to address the content of the medical school regarding ID,
8
9
10 challenging behaviour and mental health problems. The parents interviewed seemed to turn to
11
12 other sources than GPs for information, but were at the same time disoriented about where to
13
14 seek help. It is also important to look at the shared responsibility of the habilitation services,
15
16
17 GPs and other health services involved. It might be that one of the reasons for lack of
18
19 involvement among GPs is that they are "afraid to step on specialist's toes". All service
20
21 providers have a responsibility and can play an important role in recognizing ill health.
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23

24
25 Focus also needs to be pointed at the GPs that prescribed medication without on-site
26
27 examination. Interpretations of verbal information are a necessary component, especially
28
29 when the patients have troubles or completely lack adequate communication skills.
30
31 Information from people who knows the children is naturally given closely attention, but can't
32
33 fully compensate for the GPs own observation by hands, eyes and ears. As a mainstream
34
35 service GPs need broad competence, and it can be difficult to acquire knowledge about
36
37 minority groups like people with ID, in special when they have behavioural and
38
39 psychopathological challenges. The existing major classification systems, DSM-IV-TR and
40
41 ICD-10, are difficult to apply and diagnosing requires specialist multi professional
42
43 involvement [10;29]. Especially when it comes to challenging behaviour and mental health
44
45 problems among people with ID, the specialist's advices will differ, and there exists no
46
47 national guidelines. This complexity may be a reason for why GPs avoid bringing up
48
49 psychopathological or behavioural issues, or avoids involvement when this topic is
50
51 mentioned.
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56 57 **Limitations and relevance** 58 59 60

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3 Everyone in the research group read transcription of the completed interviews, and when
4 seven interviews were finished, the researchers agreed that we had met a saturation of data.
5
6 Reasons for saturation of data could rely on the fact that the participants represented a
7
8 relatively homogenous group. They were all from the same county, represented a low range of
9
10 age (10-16), received health services from habilitation services for children, and were
11
12 recruited because they had reported challenging behaviour and/or mental health problems.
13
14 This is obvious threats to external validity, and limits the immediate generalisation of the
15
16 results. Nevertheless the participants represented different diagnosis, challenges, gender and
17
18 location (rural or city), and is consistent with international research that points out difficulties
19
20 experienced by families, and problems with general health care for people with ID
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22 [\[24;28;30;31\]](#). By this our findings can have transferability and importance for further
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24 research in the field.
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33 CONCLUSION

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35 This study shows that GPs are inadequately used by families with children with ID. In
36
37 addition several health care providers are involved in every focused child, but the total health
38
39 care needs are not met by these families. The attention needs to be focused at GPs
40
41 involvement in issues like preventive screening services for somatic health, participation in
42
43 collaborative meetings and involvement in challenging behaviour and mental health problems.
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45
46

47 In general, the families investigated in this study have low expectations to their GPs, and
48
49 seldom involve their personal GP in major issues like challenging behaviour and mental
50
51 health problems. And when GPs are involved, it seems to be a temporary contribution,
52
53 although problems seem to continue for the families and their child. One explanation of little
54
55 involvement by GPs can be that paediatric department habilitation services make available
56
57 these services, and by that give the GPs an impression that health care needs are met. GPs
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2
3 have close connection to municipal services and are gate-keepers of specialist health services,
4
5 but this potential was not fully exploited by the participants we interviewed. Regular health
6
7 checks and participation in collaborative meetings can put the GP in position to be a greater
8
9 support for families with need for complex health services for their child.
10
11

12 Further research is needed to investigate factors that could influence on GPs follow up of
13
14 children with ID, and this paper addresses some issues that need to be focused in such
15
16 research. Little have been done to study how GPs interact with children with ID, and their
17
18 caregivers, and this study can pinpoint some important issues related to this field. To sum up,
19
20 the recommendations from the families involved is: i. regular GP health checks, ii. GPs
21
22 should have a broadminded attitude towards the length of the consultation, iii. GPs should be
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24 interested in every day living including the situation of the parents.
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Competing interests

The authors declare that they have no competing instructions.

Authors' contributions

TF conducted the interviews, transcribed and analyzed them. He also wrote the paper. ORH and LJD analyzed interviews. KK participated in the interviews and analyzed them. LL supervised the overall project. All authors have read and approved the final manuscript.

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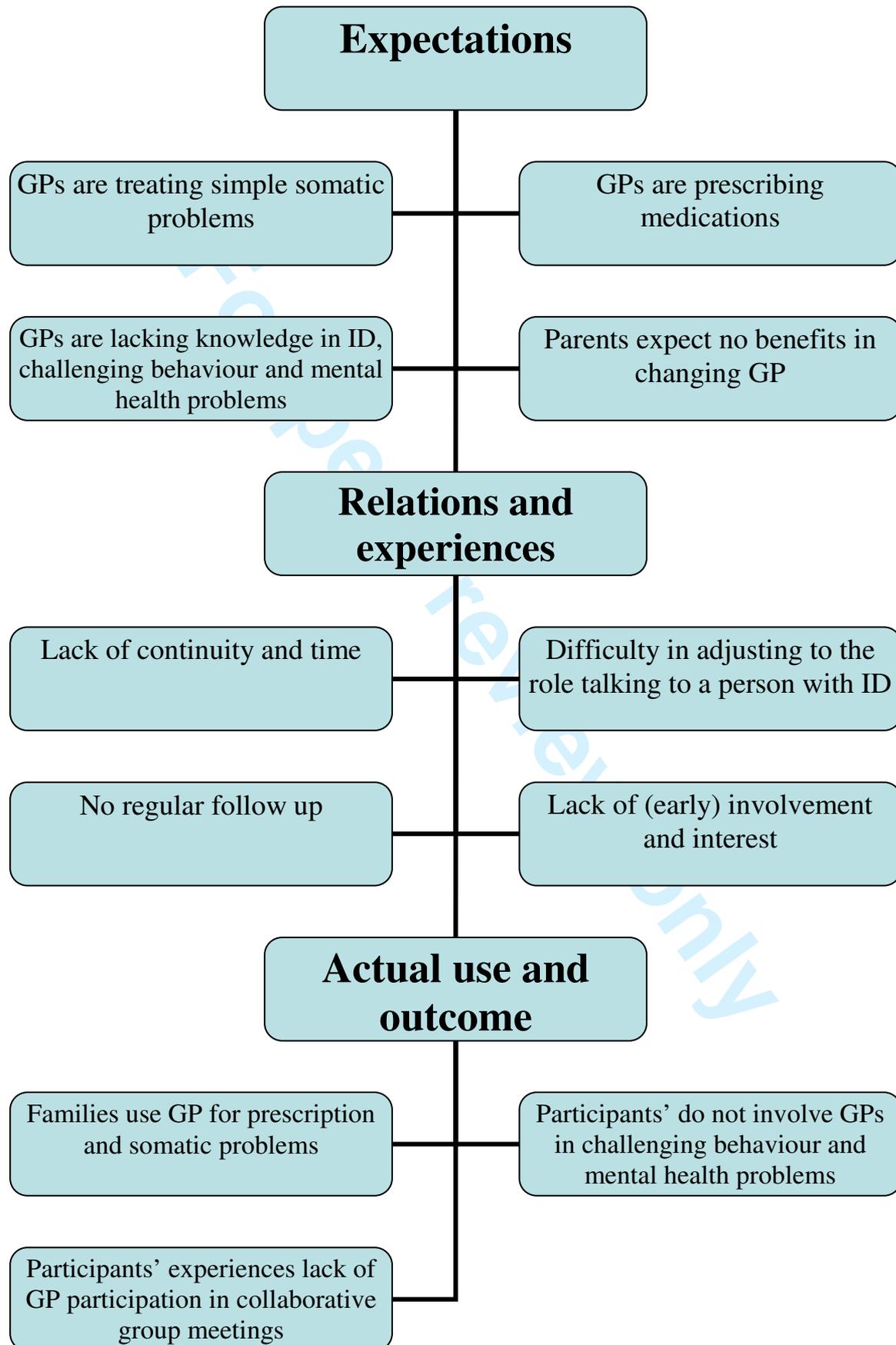
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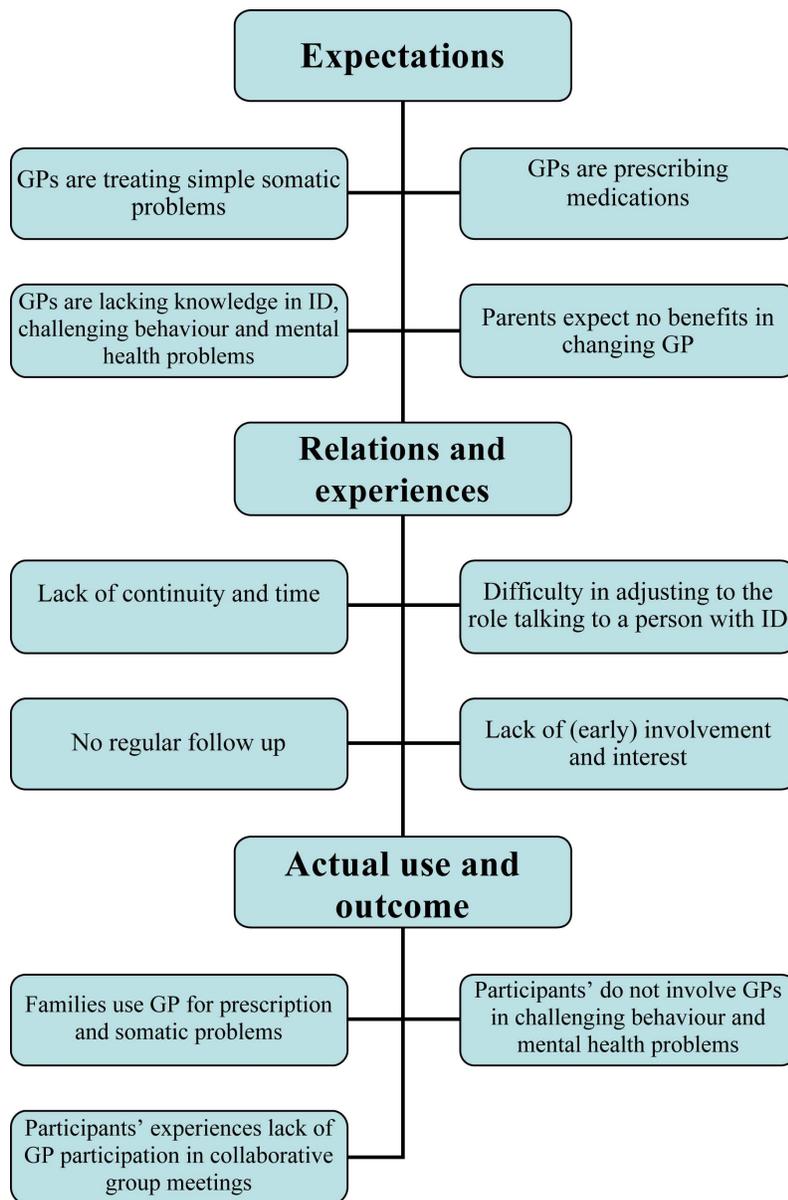
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For peer review only

FIGURE 1 *Model with themes and subthemes*





160x232mm (300 x 300 DPI)

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Research check list - Fredheim et al. 2011

Domain 1: Research team and reflexivity

Personal characteristics

1. Interviewer/facilitator 1: Terje Fredheim
2. Credentials: Master of Learning in Complex Systems
3. Occupation: PhD-student
4. Gender: Male
5. Experience and training: Participated in earlier qualitative and quantitative research

1. Interviewer/facilitator 2: Kari Kjønberg
2. Credentials: Reg. nurse, MMHC
3. Occupation: Reg. nurse specialised in mental health care.
4. Gender: Female
5. Experience and training: Participated in different earlier qualitative health research studies.

Relationship with participants

6. Relationship established: There was no relationship prior to study commencement.
7. Participant knowledge of the interviewer: They were informed about researchers' professional background and interest in the project.
8. Interviewer characteristics: The interviewers' connection with specialised health care may be regarded as bias, but was considered as a minor problem.

Domain 2: Study design

Theoretical frame work

9. Methodological orientation and theory: The study relies on a phenomenological approach with content analysis and systematic text condensation as the main method in analysing data.

Participant selection

10. Sampling: Names of possible participants were given the interviewers from habilitation services on specialised health care level. The interviewers then recruited strategically from this list to represent different gender, age, diagnosis and location (rural or city).
11. Method of approach: Participants were contacted by telephone. Information was given and request made, and appointment made with those who were positive.
12. Sample size: Nine participants were interviewed, representing seven children.
13. Non-participation: Two persons refused/hesitated to participate. No drop-outs. The reason for non-participation was not asked for.

Setting

14. Setting of data collection: Five interviews were conducted in the participants' own home, two in a meeting room at the researchers' working place, by the participants' own choice.
15. Presence of non-participants: None.
16. Description of sample: Seven females and two males were interviewed (parents). They represented seven children of various gender, age, location and health service offers.

Data collection

17. Interview guide: A guide with themes and main questions was provided by the researchers and discussed with the supervisors. Also a checklist was used to get more information on topics that seemed important or topics not mentioned by the participant. No pilot was tested.

18. Repeat interviews: Repeated interviews were not used. Participants were encouraged to contact the interviewers if they wanted to add something and one of them made contact by telephone to give some more information.

19. Audio/visual recording: Audio recording was used to collect data.

20. Field notes: The two interviewers made field notes during the interviews, and immediately after each interview.

21. Duration: Interviews lasted 60 – 90 minutes.

22. Data saturation: Saturation was discussed in the research group after the seven interviews had been conducted and was then regarded as satisfactory.

23. Transcripts returned: Transcripts were not returned to participants for comment or corrections.

Domain 3. Analysis and findings

Data analysis

24. Number of data coders: All five in the research group read the complete transcript. One of the interviewers presented identified meaningful units and themes derived from the material and they were discussed in the research group.

25. Description of the coding tree: The coding tree is illustrated with a figure of major and minor themes.

26. Derivation of themes: Themes emerged from the data.

27. Software: No additional software was used.

28. Participant checking: Participants were offered feedback on the findings. Two of them expressed a request for feedback.

Reporting

29. Quotations presented: Participant quotations were used to illustrate findings. Quotations are not identified in this paper due to a small number of participants.

30. Data and findings consistent: The themes developed by the researcher(s) were logically consistent and reflective of the data.

31. Clarity of major themes: The major themes are described in the article, and reflect the research question.

32. Clarity of minor themes: Minor themes are described in the article, and reflect meaningful units. Diverse cases are described where necessary.