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Published in:
Journal of Policy and Practice in Intellectual Disabilities

DOI:
10.1111/jppi.12443

Publication date:
2022

Document Version
Publisher's PDF, also known as Version of record

Received: 13 October 2021 | Accepted: 31 August 2022

DOI: 10.1111/jppi.12443

ORIGINAL ARTICLE

Journal of Policy and Practice in Intellectual Disabilities

Good health care for a good life? The case of down syndrome

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Funding information
Fonds NutsOhra, Grant/Award Number: 1403-029; Jeroen Bosch Hospital, Grant/Award Number: n/a

Abstract

People with Down syndrome have complex health care needs which are not always fully met. Health care improvements are required to better meet these needs. Quality indicators are an important tool for improving health care. However, quality indicators for health care for people with Down syndrome are scarce. Existing quality indicators focus on medical (physical) needs or the clinical setting, even though it is acknowledged that quality measures should reflect the *total* of quality aspects relevant to the population at stake, which may encompass aspects *beyond* the medical domain. These aspects beyond the medical domain are the focus of the current paper, which aims to provide insight into the way people with Down syndrome live their lives, how health care may fit in, and how this may impact the development of quality indicators. The paper is based on data originating from interviews with people with Down syndrome and their parents as well as focus groups with support staff members working in assisted living facilities for people with intellectual disability. The data revealed a lot of variation in how people with Down syndrome live their lives. Nevertheless, we were able to identify 11 topics, which we grouped into three overarching themes: (1) Being different yet living a normal life; (2) Down syndrome-(un)friendly society and services; and (3) family perspective. The variation in our data stresses the importance of health care that takes a person's life into account beyond the medical domain, as exemplified by the identified topics. Our findings also show that a good life is not merely depending on good health care supported by well-defined quality indicators, but on (support in) all life domains.

KEYWORDS

down syndrome, health care, intellectual disability, practice, quality of life

INTRODUCTION

Down syndrome (DS) is a common cause of intellectual disability (ID) (De Graaf et al., 2017; Phelps et al., 2012), and is related to a specific combination of health problems, behavioural profiles, and cognitive challenges (Capone et al., 2018, 2020; Coppus, 2017; Grieco et al., 2015; Weijerman & De Winter, 2010). Because of this, people with DS have complex health care needs, which are not always properly met by the health care they receive (Capone et al., 2018; Goodman & Brixner, 2013; Peters et al., 2020; Phelps et al., 2012). A complete picture of what matters to patients is required to properly answer their needs (Czypionka et al., 2020; Kelley & Hurst, 2006) and may include quality aspects *beyond* the medical domain (Czypionka et al., 2020). This is supported by our previous work that showed that parents of people with DS consider health care as only one aspect of the total of desired services and facilities (Van den Driessen Mareeuw et al., 2020).

Quality indicators (QIs) may largely contribute to obtaining such a complete picture of what matters to patients and to improving health care (Donabedian, 2005; Porter, 2010). Current developments in health care quality measurement underline the importance of measures that matter to patients (Kelley & Hurst, 2006; Porter, 2010) and that reflect the *total* of quality aspects relevant to the population and context at stake (Terwee et al., 2018). It is acknowledged that the social environment (family members, other caregivers, house mates) and the contexts in which people with ID (including people with DS) live, may all interfere with outcomes of health care (Goodman & Brixner, 2013; Kyrkou, 2018; Mastebroek et al., 2016; Simões & Santos, 2016). This is also in line with the currently increased attention to person-centred care and related shared or collaborative decision-making (Peisah et al., 2013; Poitras et al., 2018).

Despite the acknowledged importance of a broader perspective (Czypionka et al., 2020; Kelley & Hurst, 2006), most quality improvements related to health care for people with ID are focused on medical (physical) needs or the medical/clinical setting (Van den Driessen Mareeuw et al., 2017; Jespersen et al., 2018). In addition, existing QIs either cover medical care for people with ID in general, without specifically addressing certain conditions or treatment courses, or cover the support and care available in supported living facilities (Van den Driessen Mareeuw et al., 2017). The general nature of these existing QIs on the one hand and the lack of QIs covering the complete picture of what matters to patients on the other, urges for the development of DS-specific QIs, as these are currently almost non-existent (Van den Driessen Mareeuw et al., 2017; Santoro et al., 2021).

The Dutch inDicatorS-project was set up to develop QIs for health care for people with DS that are sensitive to their specific needs. This paper aims to provide insight into the way people with DS live their lives, how health care may fit, and what this means for the development of QIs. The following research question is addressed: 'What is important in the lives of people with DS, and how could this impact the development of QIs for health care for people with DS?'

METHODS

This article is based on data from semi-structured interviews with people with DS, semi-structured interviews with parents of people with DS and focus groups with support staff working in assisted living facilities for people with ID (including people with DS), which were conducted as part of a qualitative explorative study on health care quality from the perspective of people with DS and their caregivers (Van den Driessen Mareeuw et al., 2020). The study meets ethical guidelines and legal requirements.

Participants

As described before (Van den Driessen Mareeuw et al., 2020), purposive sampling was applied to ensure a large diversity of participants and obtain insights from different perspectives. Inclusion criteria for participants with DS were being able to participate in an interview, and therefore being at least 12 years of age, and to have mild-to-moderate ID. Because of their significant role in the lives of people with ID (Mastebroek et al., 2016), parents and support staff of people with DS were involved to obtain complementary information about people with DS, but also to obtain information about people with DS who are not able to participate in an interview (younger than 12, or with more severe ID).

Participants were recruited through the Dutch DS association, service providers for people with ID, and the network of the authors. All participants received participant information and informed consent forms; participants with DS received easy-to-read versions. Participants, and their legal representatives if required, gave informed consent.

Data collection

Semi-structured interviews with people with DS and with parents

The interview protocol for the interviews with people with DS and with parents consisted of an introductory

part, including information about the study and about participation in an interview, and a list of topics to be discussed, although the detail and order in which the topics were addressed differed per participant group. The topics included experiences with health care for people with DS and topics derived from the eight domains of quality of life by Schalock et al. (2005): Emotional well-being, interpersonal relations, self-determination, social inclusion, material well-being, personal development, rights, and physical well-being. Furthermore, participants were allowed to add topics they considered relevant. The interviews were conducted by one of the authors.

Participating people with DS and parents could choose the time and venue of the interview and were allowed to invite someone else for moral and/or verbal support. The abilities of the participants with DS were met by using visual materials, such as pictures of care settings, daily activities, and pictograms reflecting emotions and other abstract concepts. Furthermore, the interviewer's talking pace and phrasing was adapted to the abilities of the participant with DS, and extra time was dedicated to putting the participant at ease. Such (adapted) interviews are often used in research involving people with ID and generally result in sufficient data (Frankena et al., 2015).

Focus groups with support staff

The protocol for the focus groups with support staff was similar to the interview protocol in terms of topics discussed, but differed in terms of detail and order in which topics were discussed and attention paid to group work (e.g. listening to each other, not talking at once). The focus groups were convened by the author who also conducted the interviews.

Five focus groups with 5–12 support staff members took place in meeting rooms of the service provider where participating support staff were employed. One support staff member was interviewed individually, because he was not able to join the focus groups.

Data analysis

Data saturation occurred in both interviews and focus groups, meaning that additional interviews or focus groups did not yield new relevant information (Tong et al., 2007).

Pseudonymised transcripts were made of the audio recordings of the interviews and focus groups. Data analysis was done using the software package Atlas.ti 8 for Windows, and consisted of three steps, based on the framework analysis method (Gale et al., 2013):

1. Deductive and inductive coding (Gale et al., 2013). Text fragments of first few transcripts were labelled with codes indicating relevant information. Deductive coding included predefined codes based on quality of life domains (Schalock et al., 2005), dimensions of quality of care (WHO, 2006), and principles of patient centred care (Singer et al., 2011), allowing structuring of data. Inductive coding involved open codes, formulated based on the content of text fragments, ensuring that no themes were missed.
2. Constructing and applying an analytical framework. One-third of the transcripts was double-coded by two authors (one-ninth by authors 1 & 2, authors 1 & 3, and authors 1 & 4). The analytical framework was evaluated by comparing and discussing the attributed codes by the different authors, after which it was adapted (merging, splitting and sorting codes per theme), leading to a final framework which was applied to the other transcripts.
3. Charting data. For each code within the themes, text fragments were summarised and put in a framework matrix, allowing data interpretation. The matrix differentiated between perspectives from people with DS, parents, and/or support staff.

This resulted in themes including codes related to medical/health care aspects, but also in themes and codes related to broader issues, providing insight into the lives of people living with DS and their families. The data retrieved on these broader issues are the basis of the current paper. The data retrieved on the medical/health care aspects are published elsewhere, as well as more information on data collection and analysis (Van den Driessen Mareeuw et al., 2020).

RESULTS

Eighteen people with DS (10 female, eight male) participated in the study, ranging from 12 to 54 years old, living with their family (4) or in assisted living facilities (14), and had mild-to-moderate ID (Van den Driessen Mareeuw et al., 2020). Fifteen parents (or parent couples) of people with DS participated in the study. Their children ranged from 2 to 43 years of age (7 female, 8 male) and lived with their family (11) or in an assisted living facility (4), and had severe to borderline ID. A total of 35 support staff members participated in the study. Their clients with DS ranged from 24 to 63 years of age and had severe to borderline ID. Further details about participants can be found elsewhere (Van den Driessen Mareeuw et al., 2020).

The data providing information on the lives of people with DS resulted in three themes containing a total of 11 topics:

- Theme A—'Being different yet living a normal life', topics:

1. Activities
2. Work/School
3. Social relationships
4. Housing
5. Barriers and levers for a normal life

- Theme B—'DS-(un)friendly society and services', topics:

6. Societal inclusion and image of people with DS in media
7. Autonomy
8. Services and support
9. Balance between autonomy and healthy choice

- Theme C—'Family perspective', topics:

10. Arranging help, support, and services
11. Impact of having a child with DS

The topics are described in three paragraphs corresponding to the overarching themes. For each topic, examples are provided by means of quotes from the participants.

Being different yet living a normal life

Participants with DS indicated that they wanted to be just like others, including having an apartment of their own, having a job, having a partner and friends, and being independent. A mother (55 years) illustrated the desire of her daughter (22 years) to be like anyone else as follows: 'She really wants to be independent. [...] She sees her sisters leaving the parental home, going on holiday on their own, going out with friends. Well, she also wants that, you know'.

Activities

The participants with DS showed a varied picture of how they lived their lives. Activities mentioned by participants with DS included: school, internships, work, or activities in an activity centre for people with ID, and a large variety of hobbies, such as sports, acting, painting, musical activities, etcetera. For example, a woman with DS (54 years) described her activities for the coming Saturday as follows: 'Tomorrow I'll go for a swim, and when I'm home I'll drink coffee, and after coffee I take a shower, and then I'm going to a birthday party, of a friend'. And for weekdays: 'I'm at work during the day'. Parents and especially support staff described the lives of people with DS as quite busy. This support staff member (woman, 55 years) described: 'If I look at my two downers [clients with DS], well, they are really having a busy life, full of all kinds of nice activities'. Support staff and parents indicated that some people with DS even become overcharged with activities or are confronted with too high expectations (e.g. by parents). This mother (55 years) of a daughter with DS (23 years) illustrates these expectations: 'They've got this syndrome you know, but they all have to become like us, so I think: how is that possible?'

Work/school

During the weekdays, activities of adult participants with DS ranged from having one or more jobs, often in sheltered workshops, to activities in activity centres for people with ID. Generally, the participants with DS valued and liked their jobs or activities and their colleagues. A woman with DS (39 years) mentioned that by having a job 'We are showing that we're also there and [...] that we can also do this'. A woman with DS (23 years) points out: 'sometimes we are going for a bite with my colleagues'.

School-aged children with DS either went to a specialised school for children with ID or to a regular school where they often received extra support by specialised staff. Parents' stories varied about specialised education. Some mentioned that the quality of specialised education was low, while others reported that the switch from regular to specialised education was relieving, because the specialised school better matched the abilities of their child.

Social relationships

Participants with DS regarded (sometimes deceased) parents, siblings, other family members, and support staff as the most important people in their lives. For example, a woman with DS (41) said: 'I sometimes go to grandma by myself'. Her mother, who joined the interview added: 'to the graveyard'. Another woman with DS (54) indicated the people most important to her: 'sometimes the support staff here [in her living facility], but my brothers the

most(...) I'm happy that I still have my brothers, and my sisters in law, and my cousins'. A wide range of other people including friends, boy/girlfriends, colleagues and house mates, but also frequently visited health care providers were mentioned as important. Parents and support staff confirmed this. However, parents also noted that people described as friends by people with DS, are often friends of siblings or parents.

Opinions about the desire to have a boyfriend or girlfriend varied largely among the participants with DS. Some had one or were longing to have one, whereas others did not have one or preferred friends over a boyfriend/girlfriend. A woman with DS (32 years): 'In the past, I did have a boyfriend, but now I want to stay single'. In looking for a partner, this woman with DS (28 years) also expressed a desire to be just like others: 'So they [dating service for people with ID] are trying to find one [a boyfriend] for me... And I said: ... if only he is normal, only has a slight handicap, not a severe one'.

Housing

Experiences with housing also varied among the participants. Some people with DS were quite happy with where they lived. A woman with DS (41 years) described her assisted living facility as follows: 'like happiness'. However, others felt lonely or otherwise unhappy with where they lived. For example, a woman with DS (28 years) who lived in an assisted living facility, revealed that she was afraid of becoming lonely there and preferred her parental home: 'I'm afraid of loneliness (...) but not here [at her parents' home]'. Participants with DS who were living with their parents either preferred to stay in this situation or were excited to be 'leaving home' in the near future.

Barriers and facilitators for a normal life

Even though being just like everybody else is important for people with DS, participants acknowledged, sometimes with frustration, that having a normal life was sometimes hindered by their cognitive or physical conditions related to DS and that they needed support. A man with DS (32 years) working in a hotel run by people with ID told about his work: 'I do work independently. But I do need guidance'. Both parents and support staff explained that communication problems (e.g. speaking/hearing problems, slow information processing) impede social interaction. A mother (57 years) of a son (25 years) with DS illustrated: 'That is because he is slow, also compared to other persons with Down [syndrome], he is slow. Other people with intellectual disabilities often react much quicker and then they are finishing his sentences and he doesn't want that'. Additionally, support staff (parents to a lesser extent) brought to light that around the age of 40, people with DS become less active, possibly as a result of early ageing. A support staff member (woman, 26 years) noted: 'And I also see diminished initiative'.

Parents (sometimes siblings) and support staff offer the needed support for achieving a life as normal as possible. They provide emotional support, but they also accompany people with DS to (health)care appointments, arrange transportation to hobbies/other activities, and manage social contacts. Other mentioned examples of support offered by parents include: the formation of a group for children preparing them for school, sometimes even fulfilling the role of a schoolteacher, supporting development or arranging needed support, being involved in setting up specialised medical services, and creating sports groups for people with ID.

DS-(un)friendly society and services

Participation in society and autonomy were also considered important elements in the lives of people with DS. Although people with DS generally feel they are part of society and that their autonomy is respected, they may encounter difficulties and need extra support in these areas, as society and services may not always be DS-friendly.

Societal inclusion and image of people with DS in media

Generally, people with DS gave the impression that they felt part of society. However, people with DS, parents and support staff also reported that people with DS felt lonely, were being bullied or not accepted because of their DS. For example, a woman with DS (38 years) said: 'In the past, I was bullied at school. [...] They used this other word for syndrome, they were calling me "mongol", but I'm not a mongol, I'm just myself and I have Down syndrome. [...] But it was not easy'. A mother (49 years) of a son (13 years) pointed out: 'He [son] and this boy really had a click. This boy did not have Down syndrome, but he was at that school for a reason, had a low IQ. They wanted to make an appointment to play together, but it was never possible, I didn't know why, and finally it became clear that his mother could not accept that her son had a friend with Down syndrome and she prevented appointments'. A support staff member (woman, 59 years) revealed that other people with ID were sometimes not accepting people with DS because of their

specific appearance: 'Down syndrome is quite visible, I think that some of the others [without DS] who live here [in assisted living facility] do not want to be seen with someone with Down syndrome'. It was also noted that people in the street do not always know how to approach people with DS. This mother (57 years) of a man with DS (25 years) explained: 'People do not know how to handle [name son] and I can't blame them for that. So other people observe how we act, [...] they do as we do. For example, the hairdresser is also trying to do what we do, and that's so really nice to see. [...] But we have to set an example, because people do not know what to do'.

Furthermore, parents as well as support staff indicated that often an unrealistic or stereotypic image of people with DS is presented in the media, only showing people with DS who are quite independent and participate in society quite well and like to be in the centre of attention. A support staff member (man, 44 years) explained: 'This is what you see on TV, they all want to be on stage, they all want to grab the microphone, and being in the centre of attention'. Parents argued that this would negatively impact the societal feeling of urgency in providing support for people with DS. For instance, a mother (63 years) of a daughter (28 years) with DS argued: 'In response to [names of presenters of Dutch TV-shows involving people with DS], a medical doctor wrote in the newspaper that it was just as if it's a pity if you do not have a child with DS. Well, of course, it's not like that, you know. [...] Our daughter always needs support and guidance'.

Autonomy

The interviews with people with DS showed that they generally have freedom of choice, or are at least involved in decisions regarding housing, daily activities, work, and so forth. A woman with DS (54 years) illustrated that she may decide herself where she wants to have dinner: 'If I want to eat upstairs. Sometimes I don't want to eat with the others in the common room, when they are all arguing and all. I cannot stand that'. In some cases, a feeling of autonomy was created by parents or support staff, for example, by letting the person with DS do the talking with health care professionals during a consultation, only intervening (non-verbally) when necessary, and supporting people with DS in making their own decisions. Sometimes, in the best interest of the person with DS, they pretend the person with DS makes his/her own choices. A support staff member (woman, 26 years) explained: 'I try to make it look like as if it is their own choice, while it is also the right choice, or that they can choose between two right options'.

Services and support

Independence, autonomy and inclusion in society was much stimulated by all kinds of different services and support systems, by developmental support (in young children with DS) and 'activities that stimulate them, so they have to do more than only assembling screws, so like gardening, shopping and planning that, musical therapy'. (Support staff member [woman, 26 years]). However, there were also cases in which people with DS had to live according to the system with little room for making their own choices. For example, the mother of a woman (28 years) with DS unveils: 'She is always dependent and she always has to do as she is told. She has to go to bed when she is told to do so [...], she has to eat what is served. [...] If the group is going to the funfair, she has to join them, whether she wants it or not, because she cannot stay at home alone'.

Balance between autonomy and healthy choice

Health was promoted in all kinds of ways to improve life and participation. All participants with DS were well aware of the positive impact of medication, (medical) aids or support, such as physiotherapy, a walker, and arch support for better walking. Parents added that speech therapy, contributing to better communication skills, was especially important at a younger age. Lifestyle, especially being overweight and on a diet, was often an issue among people with DS. However, despite various medical problems, participants with DS considered themselves to be healthy. It also became clear that it was not always easy to find the right balance between autonomy and personal values and ideas on the one hand, and making the healthy choice on the other. Ideas of participants with DS about health care ranged from considering it as part of their regular schedule, to finding it tiring or not nice. Some people with DS who had a family member who had died in hospital, had developed the idea that when you go to a hospital you will die. People with DS, parents and support staff showed that (health) services and supports sometimes succeeded in finding the right balance, sometimes not. For example, a woman with DS (54 years) said: 'I may eat a bit, but not too much'. Support staff (woman, 26 years) of this woman explained: 'She has lost 20 kilos already. [...] she's got a list of what she's allowed to eat, [...] If she does well, [...] she gets a reward, like doing something nice together'. A man with DS (32) said: 'Yes, I've got arch support [foot correction]'; His mother (65 years) who joined the interview however added: 'Yes, he had, but he threw them [insoles] away'. Another

mother (55 years) explained about her daughter (23 years): 'they'll say that she has to have glasses, but she just doesn't want them and she functions well, so let it go'.

Family perspective

A child (or sibling) with DS may bring joy as well as worries to a family. Primarily parents noted the efforts needed to arrange all needed supports and services for their child with DS. Some parents manage quite well, whereas others experience the efforts as distressing.

Arranging help, support, and services

Parents play a crucial role in managing and arranging all help, support, and services needed for a good life of their children with DS. All interviewed parents mentioned problems related to this. Parents reported difficulties in identifying the needed and available services for their child in their region. They questioned what day care (for young children), developmental support, (support at) school, work, housing or other activities their child needed. A mother (41 years) of a boy (2 years) with DS illustrated: 'What do you choose, [...] which development method?' A father (63 years) of a woman (32 years) with DS illustrated: 'She needed an internship when she had finished school, or work that she could do. And then you go to the municipality and they say: we don't know, maybe you can get some support here and there. We had to find out ourselves'.

Once parents had found the right (combination of) services and supports, they encountered problems in actually arranging them. They, for example, faced problems concerning availability of services or housing. A father (63 years) of a man (32 years) with DS exemplified: 'All assisted living facilities and initiatives are full, so you're dependent on available places'. Other problems were related to the efforts needed to (financially) secure all services their child with DS was entitled to. A mentioned complicating factor was that rules and regulations were changing regularly and that different municipalities applied different rules. A mother (37 years) of a girl (7) with DS illustrated: 'How you have to apply for all the services, that's a hell of a job. [...] you have to invent the wheel yourself, [...] *it differs largely per municipality* [...] And then you think you have arranged it all for one year, but then you have to do it again for the next. [...] and then we got this discussion about whether the municipality was financially responsible or whether it was covered by some other regulation'. Additionally, parents indicated that it was quite complex to align the needed support and services, and for example, arrange transportation from and to the different services. Some parents indicated that they got assistance with aligning all support and services from a local case manager appointed by one of the organisations that provided support to their child. A father (54 years) of a boy (14 years) with DS illustrated: 'Well we put a lot of energy in that, and someone from the care organisation who was responsible for the guidance of the childminders, took the first step in aligning all these separate activities: speech therapy, physiotherapy, floating support, educational support at school, to bring them all together, and to make sure that we all had one goal for him [son with DS] at school and after school'.

The interviewed parents indicated that not all parents are capable of tackling the above problems and note that some become overburdened with it. A mother (41 years) of a boy (2 years) explained: 'We can manage, but parents who are not that assertive, not that capable of investigating all options...' Furthermore, it was mentioned that all activities require more time with a child with DS and that even when a child does not live with his/her parents anymore, many tasks are still to be fulfilled by the parents, such as cleaning the apartment of their child with DS and regulating the weight of their children. Parents (both 64 years) of a daughter with DS (28 years) explained: 'and we still have to do the rest. [...] actually, I'm busier now [since daughter moved out], but in a different way, because if she's tired, she cannot do anything. She may say that she can do the washing, but that's not totally true of course'.

Impact of having a child with DS

The impact of having a child with DS was also an issue often mentioned by parents. On the one hand, parents indicated that their child with DS made them and other family members live 'in the moment'. For example, a mother (57 years) of a man (25 years) with DS explained: 'My eldest sometimes said: If I feel stressed or not that well, then it helps me to watch [name son with DS]'. On the other hand, parents revealed that they had had difficulties accepting the diagnosis 'Down syndrome' and that they sometimes found it confronting to see children of the same age without DS or to face information about DS. They also added that they had learned to live with it. A mother (49 years) of a boy (13 years) with DS illustrated: 'fortunately, you get used to it, [...] but my niece who is two years younger than [name son with DS], that's quite confronting. Then I think, shit, she can do this, she can do that, all independently'. Additionally, parents

noted that siblings of people with DS are sometimes forgotten because all attention goes to the child with DS.

Some parents were quite worried about the future of their children with DS, while others were confident that they had made, or would make, the right arrangements for the future. Worries often had to do with their children moving out, or with themselves not being there anymore. For example, a mother (55 years), of a woman (23 years) with DS said: 'Yes I'm worried, whether she will get the attention she needs, when she is going to live there [in an assisted living facility]' Another mother (63 years) illustrated: 'All parents are bothered with this: what if we cannot do it anymore?' Parents made several arrangements for their children, ranging from building social networks to establishing legal arrangements. For example, a father (63 years) of a man (32 years) with DS said: 'We have this social network around him, partly paid by this regulation, and then there is family living nearby [...] so if we fall out, he will be known and recognised in our village'. A mother (63 years) of a woman with DS (28 years) added: 'two legal representatives [...] and we're currently drafting a will'.

DISCUSSION

This article provides insight into how people with DS in the Netherlands live their lives, how their lives are supported, and what this may mean for their parents and other family members. This insight draws the broader context within which the development of quality instruments for health care for people with DS, such as QIs, should take place (Kelley & Hurst, 2006).

This article shows aspects of the life of people with DS that may directly or indirectly interfere with health care. An example of a direct connection to health care can be found in the given examples regarding medical aids, such as arch support or glasses. This involves finding the right balance between autonomy and personal values and ideas on the one hand and making the healthy choice on the other. From the medical point of view, medical aids may be a good idea (healthy choice). However, if a person with DS does not accept the aids or is not experiencing a functional problem ('autonomy, personal values and ideas'), this may not be the best option. Therefore, before describing aids, it would be helpful to investigate whether the person with DS (and his/her carers) accepts such aids, which guidance may be needed, and whether alternatives are available. Another example is the aspect of 'wanting to be just like others'—which was considered to be quite important by the study participants, but also by other people with ID (Sandjojo et al., 2019). Its importance is also reflected as a *right* to be like others in the Convention on the Rights of Persons with Disabilities (CRPD; UN, 2006). One participant with DS in the current study wanted to deploy the same activities as her siblings without DS and another explained that by having a job she showed that she was just like others. If accepting medical aids would enhance the feeling of being different, and not being as others, this could be a reason for refusing such aids. Health care professionals should take such issues and desires into consideration to contribute to the quality of life of their patients with DS. By doing this, they would also respect the CRPD (UN, 2006), which advocates support needed to establish equity.

Achieving the right balance between 'autonomy/values/ideas' and the 'healthy choice' demands a person-centred approach (Langberg et al., 2019; Morgan & Yoder, 2012; Poitras et al., 2018). Person-(or patient) centredness is multi-faceted but is generally built upon three overarching elements including the person's situation, the professional-patient/person relationship and coordinated care (Langberg et al., 2019; Singer et al., 2011), which are also reflected in the findings of this study. In many literature, person-centredness also involves shared decision-making practices, in which health care professionals collaborate and share responsibilities with their patients and the people around them to find the option that best fits the preferences, values and context of the patient (Langberg et al., 2019; Peisah et al., 2013). Our data show that people with DS are able, to a certain extent, to act and decide autonomously, and that their parents, other family members and support staff support them. Such 'collaborative decision-making' practices (Peisah et al., 2013), as part of a person-centred approach, will also include and respect the situation of parents, which may be, as our findings show, quite challenging. The same holds for most parents and families having a child with ID (Staunton et al., 2020). Taking into account such contextual factors may positively impact health outcomes (Poitras et al., 2018). Moreover, by sincerely seeing and listening to people with DS, their autonomy is respected (Peisah et al., 2013), which is important because it contributes to a feeling of being seen and a feeling of being 'just like others' (Sandjojo et al., 2019).

Having said this, our findings also show that there is a lot of variation between people with DS. Although specific health problems, behavioural profiles and cognitive challenges are more common among people with DS (Capone et al., 2018; Capone et al., 2020; Coppus, 2017; Grieco et al., 2015; Weijerman & de Winter, 2010), each person with DS is unique. By striving for as much variation in the participant characteristics as possible (Van den Driessen Mareeuw et al., 2020), we attempted to capture as many different meanings, impacts, and

perspectives as possible. Despite this, we could not avoid underrepresentation of people with DS with severe ID in our study population, which may have introduced some bias. Perhaps, applying additional methods especially suited for people with limited verbal skills would have diminished this (Frankena et al., 2015). We did, however, include several parents and support staff from people with DS with severe ID. Nevertheless, the richness of the data and the broad range of insights we were able to unveil, underlines again the importance of looking into a person's life, beyond the medical domain, to provide effective health care and establish 'QIs that matter to patients'. At the same time, the data also show that a good life is not merely depending on good health care, but that it involves all life domains (Schalock et al., 2005). This not only means that health care professionals should respect all these domains and look for collaborations with other domains, but also that professionals, and informal carers, from all sectors should collaborate and seek for joint initiatives to support people with DS in living their lives. In fact, this calls for a more supportive society, in which all people, including people with DS, can participate in their own specific way. As part of this, and in accordance with the CRPD (UN, 2006), families should be supported in the care for their family member with DS, for example, by investing in personal coordinators. Especially since our findings acknowledge the key role of the family in enabling people with DS to participate in society. Extra family support could alleviate the struggles families experience with respect to arranging all services and supports needed for a 'normal life' and participation. Similar issues are seen in families with a child with ID, as well as the need of good family support, which is not always sufficient (Staunton et al., 2020).

The findings of this study put QIs for health care for people with DS in a wider perspective. QIs are not the panacea for a supportive society, they can however contribute to it if they are developed in harmony with this wider perspective and as part of a larger whole. This implies that the QIs should reflect this wider perspective and should not only cover medical measures (e.g. whether a timely cardiac ultrasound took place), but should also include aspects related to coordination, collaboration, and person-centredness. QIs may for instance use electronic health insurance claim data to measure coordination and collaboration (Uddin et al., 2015). Such QIs may stimulate health care professionals to synchronise provided care with the person's life and his/her social and institutional context. In that sense, QIs contribute to improving health care (Donabedian, 2005; Porter, 2010) and thereby to better lives of people with DS. This 'outward-looking' approach of health care (professionals), which may be stimulated by QIs, might also have a positive effect on health care for people with ID without DS, especially since previous research showed that QIs on health care for people with ID are scarce or cover other services than medical ones (Van den Driessen Mareeuw et al., 2017). Consistent with the current findings, the medical domain concerning people with ID does not seem to be connected with other services. A more 'outward-looking' and holistic approach of professionals in health care for people with DS, as stimulated by QIs for health care for people with DS, might set an example for health care for people with ID.

CONCLUSION

In an era in which health care and QIs ought to matter to people, a broader perspective, beyond the medical domain, should be applied. This study shows what this may encompass regarding people with DS as it provides elaborated insight into the lives of people with DS. QIs for health care for people with DS should reflect this broadness to contribute to their lives and should be introduced as part of a larger system, fostering, among other things, person-centredness and intersectoral collaboration. The findings may also apply to quality of health care for other people with ID.

ACKNOWLEDGMENTS

The authors would like to thank all participants in the study that yielded the data for this publication for their time and willingness to share their opinions and experiences. Also, the authors would like to thank all actors involved in recruiting participants.

CONFLICT OF INTEREST

The authors declare that they have no competing interests.

ETHICS STATEMENT

The study that yielded the data for this publication was approved by the Ethical Committee of the School of Social and Behavioural Sciences of Tilburg University (Tilburg, The Netherlands) on August 21, 2016 (no. EC-2016.21), and meets ethical guidelines and legal requirements. We have obtained informed consent from all participants in the study.

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How to cite this article: van den Driessen Mareeuw, F. A., Coppus, A. M. W., Delnoij, D. M. J., & de Vries, E. (2022). Good health care for a good life? The case of down syndrome. *Journal of Policy and Practice in Intellectual Disabilities*, 1–11. https://doi.org/10.1111/jppi.12443