



# A supporting role: Mothers' perceptions of their child's developing awareness of Down syndrome

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## Abstract

**Background:** Young people with Down syndrome and their families often contend with social stigma. The present study examined this issue from their mothers' perspective.

**Methods:** An interpretative phenomenological approach (IPA) was used to explore mothers' perceptions of their child's developing awareness of their disability and associated social stigma. Interviews were carried out with nine mothers of young people with Down syndrome aged 9–16 years old.

**Results:** All mothers were sensitive to the stigmatized status of Down syndrome and were at pains to protect their child from becoming aware of it. Some mothers had talked about Down syndrome with their child. Other mothers carefully monitored their child for signs that they were ready to talk about it. On the surface, all mothers believed that their child had a limited insight into Down syndrome and stigma but detailed discussion revealed more complex insights.

**Conclusion:** Mothers expressed uncertainty and anxiety about when and how to talk to their child about Down syndrome.

## KEYWORDS

attitudes, development, down syndrome, identity, mothers, stigma

## 1 | INTRODUCTION

Goffman (1963) noted that stigmatized individuals possess an “undesired differentness” that sets them apart from “normal” society (p.15). As a result, they are seen as lesser persons (Crocker, Major, & Steele, 1998). Intellectual disability is a stigmatizing characteristic. As a consequence of being stigmatized people with intellectual disabilities can be subjected to a number of negative social experiences, such as name calling, being stared at and being excluded from social situations (Mencap, 2007; Scior & Werner, 2015).

Down syndrome is the most common genetic condition causing intellectual disabilities (Sherman, Allen, Bean, & Freeman, 2007).

People with Down syndrome have singular physical characteristics, most notably the epicanthic fold that gives them a distinctive eye shape. This means that people with Down syndrome are easily identifiable to others, making them particularly vulnerable to stigmatized treatment (Goffman, 1963). The visibility of their condition may also have implications for how individuals with Down syndrome see themselves. Despite this, very little research has been carried out to investigate how or if children and young people with Down syndrome become aware of their condition and/or its stigmatized status (Deakin, Moore, & Jahoda, 2018).

Cunningham, Glenn, and Fitzpatrick (2000) carried out one of the few studies to address this issue. They asked young people aged 17–24 years old to sort photographs of other young people who

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either had or did not have Down syndrome into piles according to which “go together.” The researchers also interviewed a parent of each young person in order to ascertain if they had told their child about Down syndrome. Cunningham et al.’s key finding was that a young person’s verbal mental age (as measured by the BPVS-II; Dunn & Dunn, 2009) predicted both whether or not they demonstrated an awareness of Down syndrome in the photograph task and whether their parents had disclosed the diagnosis to them. On the basis of this finding, Cunningham et al. argued that a child’s awareness of Down syndrome is determined primarily by their cognitive level and that parent’s disclosure of Down syndrome is responsive to their child’s abilities and needs. They stated that a verbal mental age of at least 5 was necessary for a child to be aware of Down syndrome.

Parents who had talked with their child about Down syndrome usually did so after their child raised the issue. Some parents reported that their child had drawn attention to their resemblance to someone else with Down syndrome. Other parents said that their child had asked why people were staring at them or why their lives were restricted compared to those of their siblings. Few parents reported taking a proactive approach to talking with their child about Down syndrome. The explanations parents gave their children about Down syndrome tended to revolve around the characteristic facial features, having additional educational support needs and/or related health issues.

In a recent study of children and young people’s awareness of Down syndrome, Saha, Doran, Osann, Hom, Movsesyan, Rosa, Tournay & Lott (2014) used a free-play paradigm with dolls representing a typically developing child and a child with Down syndrome. They found that most participants with Down syndrome, who were aged between 4 and 17 years old, showed a preference for playing with the typically developing doll. Participants also expressed more positive views about the typically developing doll compared with the doll who had Down syndrome. When asked which doll looked most like them, they chose the typically developing doll. Saha et al. suggested that children with Down syndrome are aware of Down syndrome and the associated social stigma.

Deakin, Moore and Jahoda. (2018) asked young people with Down syndrome to choose the photograph of who they would prefer

to engage in a number of activities with. They found that children and young people with Down syndrome expressed a preference for socializing with those who did not have Down syndrome. This finding suggests that the children and young people were not only able to discriminate between those with and without Down syndrome but were also aware of the negative stereotypes attached to Down syndrome. However, these negative views of Down syndrome were not internalized, as the children and young people with Down syndrome were found to hold positive views of themselves.

Parents are in a unique position to observe their offspring over time, within the family context. This means they may have important insights into whether their child is aware of Down syndrome and the social stigma associated with it. They may also be able to provide an account of how such an awareness emerges. However, they are not merely observers but play a vital role in helping their child to negotiate and understand their place in the world. This qualitative study explores the views of mothers of the young people who participated in Deakin, et al. (2018) research. The main areas being explored concern mothers’ views and experience of helping their children to understand their Down syndrome. In this context, the mothers’ beliefs about their child’s awareness of Down syndrome and their feelings about it were also explored.

## 2 | METHOD

### 2.1 | Participants

Nine mothers aged 39–48 years old participated in the study. All were biological mothers of their child with Down syndrome. Five were mothers of a daughter with Down syndrome and four had a son with Down syndrome. The participants’ children were aged 9 to 16 years old. All of the children had at least one typically developing sibling. With one exception, the mothers were living with their marital partner. Table 1 shows background information about the mothers, their children and where their child went to school. Pseudonyms for the mothers and their children are used throughout. Families

**TABLE 1** Demographic information on participants and family composition

Mother (age)	Child (age)	Siblings (age)	Primary education	Secondary education
Caroline (41)	Henry (15)	Mary (15)	Mainstream	Special
Gail (46)	Daniel (16)	Nick (18)	Mainstream	Special
Sheila (40)	Sophie (14)	Tania (16); Luke (12)	Special	Special
Tessa (48)	Abbie (9)	Mark (12)	Mainstream	
Sarah (42)	Peter (12)	Eoin (16); Arnie (15)	Mainstream	Mainstream base
Tracy (46)	Harry (10)	Roslyn (15)	Mainstream	
Anne (39)	Lydia (10)	Nathan (7)	Mainstream	
Lorraine (40)	Fiona (13)	Boris (2); Peggy (12)	Mainstream until Primary 6	Special
Michelle (42)	Lucy (15)	Hannah (19)	Mainstream	Special

were contacted through schools in the West of Scotland and Down Syndrome Scotland, a charitable organization. The participants were the first nine mothers contacted who agreed to take part.

## 2.2 | Procedure

All participants chose to be interviewed at home and gave permission for the interview to be recorded. Demographic information was collected at the end of the interview, when the recorder had been switched off.

Semi-structured interviews were used to gain insight into how mothers supported their children in relation to understanding their Down syndrome. The mothers' views of their child's awareness of Down syndrome and sense of difference were also explored. The interview topic guide was designed to elicit mothers' views about their child's developing awareness of Down syndrome and difference. While the topic guide was used to help structure the dialogue, the interviewer remained alert to other topics or concerns raised by the participants and explored these when they arose.

The interview began with general questions about family composition and family life. Mothers were then encouraged to talk about their experiences with their child with Down syndrome when they were born and in their early years. The researcher ensured that sufficient rapport had been developed with the participant before asking about their child's relationships with others. The interviewer then addressed the child's relationships with siblings and school peers, and how these may have changed over time. Mothers were also encouraged to describe if and how Down syndrome and/or disability had been spoken about as a family or discussed directly with their child with Down syndrome. If the subject had been discussed, mothers were asked about their child's understanding and feelings about Down syndrome. Mothers were asked about any instances of stigma their family may have experienced. In addition, mothers were asked if they thought their child was aware of discriminatory attitudes. The final section of the interview explored the mothers' hopes for their child's future.

The interviews lasted between 45–90 min.

Ethical permission for the study was obtained from the ethics committee of the University of Glasgow.

## 2.3 | Qualitative analysis

Interpretative phenomenological analysis (IPA) was considered an appropriate method to explore mothers' perceptions of their child's awareness of Down syndrome (Smith, 2004). In IPA it is recognized that the researcher must interpret the participants' perspectives in the context of their lives. Thus IPA allows for a highly descriptive and in-depth account of participants' experiences. Finally, IPA has also been used successfully in previous research concerning highly sensitive topics with the parents of people with intellectual disabilities (Reilly, Huws, Hastings, & Vaughan, 2008).

Interviews were transcribed verbatim by the researcher and the analysis followed the steps described by Smith and Osborn (2008). The process began with the researcher becoming familiar with the content of the interviews. The researcher then noted points of interest and significance. The next step involved capturing emerging themes. A set of emergent themes and relevant quotes from the transcript was subsequently compiled, and connected themes were grouped and organized under over-arching theme headings. This process was repeated for each transcript. The resulting over-arching themes for all interview transcripts were then compared and integrated. Finally, a table of the emergent themes was compiled.

The researcher took the following steps to ensure the analyses were carried out rigorously. (a) a reflective journal was used to chart the process of drawing out and integrating themes across the transcripts, (b) a summary of each interview was produced to help ensure the themes reflected the complexity and detail of the participants' narratives as a whole. (c) the interviewer recorded reflections after each interview to allow the emotional reactions of the interviewees to inform the interpretation of the transcripts, (d) an experienced IPA researcher oversaw and audited the process of analysis, this included double coding initial transcripts and discussing all the

Mothers who had told	Mothers who had taken a less direct approach
Getting "in there" first	Not hiding Down syndrome, but waiting on them to show us they are ready to talk about it
Downplaying the significance of Down syndrome	Disclosure amounts to breaking bad news
Down syndrome not central in the family context	Don't engage with the words "Down syndrome"
They know about Down syndrome, but they are just empty words	They show no sense of awareness
They have noticed facial similarities	Never treated as different
Awareness of stigmatized treatment	Doubts emerging: there are some signs of awareness

**TABLE 2** Summary of themes identified from two groups of mothers

emerging themes from across the sample of participants, and (e) finally, care was taken to return to the original transcripts to check the themes were grounded in examples from the interviews (Reid, Flowers, & Larkin, 2005).

### 3 | RESULTS

The mothers' accounts indicated they had taken one of two approaches to the disclosure of their child's Down syndrome. Two mothers described having taken a direct approach to telling their child about Down syndrome. The remaining seven mothers explained that, while they did not hide the fact their child had Down syndrome, they had not made a deliberate attempt to tell their child about it. Since these approaches seemed to represent two distinct experiences from the child's perspective, the data were analysed separately. The themes identified in the accounts of both groups of mothers are summarized in Table 2. The themes identified from the two mothers who had taken a direct approach to telling their child about Down syndrome are presented first.

#### 3.1 | Part 1: Themes from the accounts of mothers who had told their child about Down syndrome

##### 3.1.1 | Theme 1: Getting "in there" first

Both Lydia's and Lucy's mother explained that they had decided to tell their daughters about Down syndrome because they were worried that they would hear it from someone outside the family home and could be upset or confused. Rather than risk that happening, these mothers preferred to take control by getting "in there" first. For example, Lucy's mother said:

... I only mentioned the words Down's Syndrome a few years back to Lucy and the only reason I done it then was because I was frightened she heard it from someone else and didn't understand it

(Lucy's mother)

Lydia's mother explained that a young person in the neighbourhood had made a derogatory comment about her daughter to another young member of the family and that this had prompted her to tell. This event highlighted to Lydia's mother that young people in the area were noticing her daughter's difference and could have broken the news an uncaring way.

##### 3.1.2 | Theme 2: Downplaying the significance of Down syndrome

The mothers had, however, placed tight limits on the information they gave to their child about Down syndrome. They introduced the

words "Down syndrome" and linked it to intellectual impairment, but this was as far as they wanted to go.

...I sat her down and I went, I just told her when she was a little baby she was born with this em thing and it was called Downs Syndrome, but, it wasn't very important, she didn't need to know much, it just meant it was a wee bit harder for her to learn things

(Lucy's mother)

While Lydia's mother was painfully aware of the reality of the broader social implications of having Down syndrome, she did not want her daughter to feel different. She spoke of how her strategy had been to normalize Down syndrome by explaining to her daughter that it was just one of the many differences that exist among individuals. In this way, Lydia's mother had disclosed her daughter's condition to her but circumvented the social significance of it. Lydia's mother stated that she had told her daughter as much as she wanted her to know, in the kindest way.

I told Lydia that she had Down's Syndrome, just like her cousin has asthma and I explained it a bit like that to her

(Lydia's mother)

However, Lydia's mother remained anxious about how the family would deal with the issue in the future, as it may not always be within their control.

...I think we've always treated her as much as possibly normal as possible so that she doesn't feel different, but the reality is she is, so we've told her that in the best way we can that everybody's, not everybody's the same anyway, so, and just tried to explain it... and probably as she gets a bit older we will go a bit more depth with it but I'd say that's kind of how we've coped with it

(Lydia's mother)

##### 3.1.3 | Theme 3: Down syndrome not central in the family context

Both mothers were keen to make it clear that their child's Down syndrome was inconsequential within the family, and, as a result, something that was rarely talked about.

I'm sounding here as if we talk about it all the time but we don't, it's, Lydia is just Lydia

(Lydia's mother)

Lucy's mother emphasized that Down syndrome was an incidental part of her daughter within the family. This appeared to be linked

to a rejection of the widely held stereotypes of people with Down syndrome.

... I've never focused on it, I've never made it a big deal, I've never wanted it to be who Lucy was. She always has been and always will be Lucy, she just happens to have Down's Syndrome [and later] ... when you have a child you don't get to look in a crystal ball and see what they're going to look or be like but if you have a child with Down's Syndrome, people assume they're all going to be the same and look the same because that is what society does think

(Lucy's mother)

### 3.1.4 | Theme 4: They know about Down syndrome, but they are just empty words

Both these mothers believed that their child's understanding reflected what they had been told. They had Down syndrome but it was of no particular consequence. For example, Lydia's mother said that her daughter knew the term Down syndrome meant she found school work more difficult, but suggested that the label held no greater meaning to her.

She knows it's there and as I say she'll explain sometimes, she'll say "Oh they mental maths, I couldn't do it mum, you know how I've got the Down's syndrome, oh it's hard" [laughs]

(Lydia's mother)

Crucially, both mothers believed that their daughters did not feel "different" and were unaware of the social significance of Down syndrome. Lucy's mother was resolute in her belief that her daughter did not feel different and stressed that she did not want her to.

...She doesn't see herself as any different whatsoever. She doesn't see herself different from me, different from Hannah [elder sister], no, she doesn't at all, but I wouldn't want her to,

(Lucy's mother)

Lydia's mother believed that her daughter was oblivious to any differences between her and her peers. She described watching her daughter struggling at a school sports day. Although this was painful to watch, she believed that Lydia was unaware that her performance differed from that of her peers. The inference was that if Lydia was oblivious to the fact that others knew she was cheating, then how could she be aware that others saw her as different?

...but at sports day it was a surprise, she ended up winning this year because they did the sack race so Lydia just carried the sack and ran and she won so that was great! [laughing] ... But she doesn't, like she wasn't embarrassed that she was running herself holding the sack and everyone else was in it, she didn't think "Oh that's not right" She said "I won" and I said "Yeah right you did!", it's the first time she's done anything like that. So I don't know that... it doesn't bother her.

(Lydia's mother)

### 3.1.5 | Theme 5: Noticing facial similarities

However, while these mothers did not think their child had any sense of being "different," they both described incidences where their daughters had identified themselves as similar to others with Down syndrome. For example, Lydia's mother said:

what I have noticed, ...a few years ago when we were on holiday, and there was another little girl and we were in a holiday camp and Lydia spotted her and she said "That little girl's the same as me"...So she can see it I would say because she's done that a couple of times.

(Lydia's mother)

Similarly, Lucy's mother described occasions when Lucy excitedly announced that a girl with Down syndrome she saw "looks like me" and "has my face." Their daughters' awareness of similarity to others with Down syndrome may not have caused concern because it did not appear to signal a sense of difference.

### 3.1.6 | Theme 6: Noticing stigmatized treatment

Despite downplaying the impact of negative social attitudes, Lucy's mother reported that her daughter was frequently stared at and she was acutely aware of it happening. Staring appeared to threaten the distance Lucy's mother had placed between her child and the social stigma associated with Down syndrome. Staring caused anxiety because she could not reveal the real reason for the staring without also telling her child that others thought she was different. Instead, when Lucy noticed she was being stared at, her mother created a "cover-up story"; she told her daughter people were looking at her because she was beautiful. However, her mother foresaw this becoming increasingly difficult as Lucy grew older.

Lucy is very aware, she's asking me why are people looking at her. When she's older, maybe I should be saying to her, no I would never say "People are

looking at you because you have Down's Syndrome, because then I would need to say that people with Down's Syndrome, and I don't want Lucy to think that she does look different from people. We're all different, I'm different from you, I'm different from my neighbour, I mean we're all different, there's no two of us the same. Maybe when she's older, obviously I would say to her but as she gets older the staring is going to get much more annoying to her.

(Lucy's mother)

Thus, while the mothers of Lydia and Lucy tried to minimize the impact of Down syndrome on their children's sense of self, there was an awareness that this may not always be under their control. It was also evident that the possibility of their child feeling different was often too painful to contemplate.

### 3.2 | Part 2: Themes from the accounts of mothers who had not told their child about Down syndrome directly

The remaining seven mothers described how they talked openly about Down syndrome at home but had not addressed the issue directly with their child. The narratives of this group of mothers were complex and fraught with tensions.

#### 3.2.1 | Theme 1: Not hiding Down syndrome, but waiting on them to show us they are ready

These mothers appeared to want their child take the lead and develop an awareness of Down syndrome at their own pace. Harry's mother described her views as follows:

... no I think we just sort of try and keep it as open as possible, any opportunity that I do have to talk about it I will, but yeah, I've not really sat him down and I haven't sat him down for a big talk or anything yet, just kind of trying to try and do it naturally as we go along sort of thing, but as I say he's just not got to the stage of asking questions yet about that,...

(Harry's mother)

#### 3.2.2 | Theme 2: Disclosure amounts to breaking bad news

Another reason for the reluctance to raise the issue themselves seemed to be because they regarded telling their child about Down syndrome as akin to "breaking bad news" and telling their child that they are different from others. Mothers believed talking about Down

syndrome would be hurtful to their child and therefore they did not want to do it. Sophie's mother believed her daughter was unaware of Down syndrome and that telling her about it would cause her unnecessary distress.

...she's never ever asked and I've never actually sat down with her and says "Sophie you're different", because it doesn't bother her just now and I don't see why I should make her all confused or get her upset or you know...

(Sophie's mother)

The mothers' belief that talking about Down syndrome would cause hurt and undermine their child's sense of self, suggests that they viewed Down syndrome as a potentially socially damaging label. Henry's mother described her concerns about raising these issues:

...why should it be, but that's the difficulty, what do you say to your son, well you need to know that you're really different from other people...why am I going to say that to him? Why would I, why would I, I don't know, it would just hurt his feelings, I don't see the point in that. If I thought I should do then I would, but I don't really think I should. But I will be honest with him, if he asks a question, then I will answer him. But, I just don't want to impose what I think on him, you know...

(Henry's mother)

However, in a similar way to the mothers in the previous section, she felt more comfortable using naturally occurring situations to talk about his Down syndrome.

But we do, see if there is, it's like that, it's where Henry's saw somebody and said you know, "he looks funny", Dan (child's father) is quite honest and will say, "Well actually he looks a bit like you Henry", and I'll do that as well, if that situation arose.

(Henry's mother)

#### 3.2.3 | Theme 3: They don't engage with the words "Down syndrome"

Mothers described how their children did not engage with the term Down syndrome. They struggled to understand why their son or daughter showed little reaction to these words, perhaps because Down syndrome had taken on major significance for them.

And again, as I've said before, we've said before, Henry do you know you've got Down syndrome? And he just kind of looks at you, you know, told you what

that means, that's why it's a bit hard for you to do maths and stuff, he doesn't really take it on at all. I don't know why...

(Henry's mother)

While, on the one hand, their child's unresponsiveness to the term seemed strange, it also corroborated their view that they were not ready to talk about Down syndrome yet.

### 3.2.4 | Theme 4: No sense of difference

Mothers believed their child felt no different from others. For Sophie's mother, her daughter's unawareness of facial characteristics indicated that she was not aware of difference.

...if she's putting on makeup, she's never ever says to me or Julie or Steve, I'm different. You know it's, she just sees herself as herself to be quite honest

(Sophie's mother)

Fiona and Harry's mothers thought that their children's unrealistic career aspirations highlighted their lack of awareness about their Down syndrome. While they were pleased that their children retained this positive outlook, they were also anxious that their children may face disappointment in the future.

he worries me slightly that, well maybe it's a good thing, that he doesn't, but it worries me that he's got such ambition for what he's going to be able to do when he's older. Which maybe that's a good thing and maybe he will be able to do it at some level, no, I think he sees himself very much as part of the crowd and part of everyone else, you know

(Harry's mother)

Abbie and Sophie's mothers described how their child attended a different school to their non-disabled siblings, were given different school work from their mainstream peers and were routinely taken out of a mainstream classroom for individual support sessions. They believed that their children were largely unaware of these differences and expressed bewilderment that their child had not questioned such differential treatment.

Abbie's doing different work at school, and I don't talk to her about that, why she's doing different work and, but she never ever comments on it, so she never volunteers any information, anything that suggests that she recognises the difference

(Abbie's mother)

### 3.2.5 | Theme 5: Never treated as different

The mothers often explained that they had always endeavoured to treat their child with Down syndrome no differently from their siblings as they had grown up, despite their difficulties. They appealed to these efforts in an attempt to explain why their child was seemingly unaware of negative social stereotypes associated with Down syndrome.

I don't know if that's because Sophie's never been treated different, you know, I've never made any exceptions although it was a struggle for her to walk, talk and so on, she was treated the exact same as the other two...

(Sophie's mother)

Similarly, Henry's mother believed that the mainstream schooling her son experienced may explain why he did not seem to notice what was so apparent to her.

I don't know really, that was a problem, that was actually a problem with us sending him to mainstream school I think, that he was in a class full of ordinary, ordinary, you know, there's a big mixture there anyway, but ordinary people em, and he just saw himself as one of those people

(Henry's mother)

There was a sense that while mothers did not want their child to feel different, it unsettled them that they seemed to lack insight into their Down syndrome. Sophie's mother suggested that her uncertainty would be resolved by her daughter asking about Down syndrome.

I mean I would love Sophie to be able to say to me, well I look different but...but see she's never ever been treated different either, she been brought up just, like a normal child...

(Sophie's mother)

### 3.2.6 | Theme 6: Doubts emerging: there are some signs of an awareness

There were considerable tensions in the mother's narratives about their child's awareness of difference. On the one hand, as the quotes above have suggested, they believed their child was unaware of their Down syndrome and did not engage with the words "Down syndrome," and mothers were able to reason about why this was the case. However, they were also uneasy about it, perhaps because they could not be sure.



Abbie's mother described the frustration felt by her daughter in relation to communication difficulties and suggested that this may have triggered some awareness of difference, especially in comparison to mainstream peers.

I think she gets frustrated because she can't do things but she hasn't identified, well that's what I think it is, she's frustrated by, she knows that she can't do things that other kids her age can do, um, and she gets frustrated when she can't do it, like speech, if she can't remember something, she'll be telling you something and she'll forget the word for it, ... and I think that's part of the, I think there's an element of in there, I can't do this, why can't I do this and everybody, because she sees everyone around her...I mean, it's stupid, I forget that, then I see, I hear all the kids in her class talking to their parents and I realise how wide the divide is, because I do kind of forget that Abbie isn't the norm, and so, her daily experience must be one of, where she thinks, there must be so much that's happening that she recognises she can't do...

(Abbie's mother)

Sophie's mother described how her daughter hid her face when passing young people on the street, a self-conscious behaviour that may have suggested that she felt negatively judged by others.

if someone is staring at her and she starts to feel uncomfortable, say we're in Mac Donald's or a restaurant or whatever, it's just she'll start that, you know the rocking, that's her getting agitated and you are like kind of looking round, right who's been annoying her, you know, and it could be someone in that corner and Sophie's caught their eye but they've not took their eyes off of her. And then she'll just start acting up and it's a case of uh we go

(Sophie's mother)

The staring that Sophie and her family experienced in the local community was a source of significant stress. Sophie's mother had to deal with the distress it caused her and Sophie's siblings, and it was very painful for her to think about Sophie's awareness of it. Later in the interview, Sophie's mother again revealed her inner conflict about Sophie's awareness of her disability. As soon as she reported that there might be an element of insight in her daughter's behaviour, she quickly reverted to the less painful conclusion that she is in fact lacks awareness.

I think she's aware that there's something, but she's never ever asked and I've never ever said because until she says to me, then I can sort of, you know,

go on, but I think she's actually oblivious to be quite honest.

(Sophie's mother)

Many mothers appeared to find it too emotionally challenging to talk to their child about Down syndrome.

Later in her interview, Sophie's mother she began to express doubts that her initial reasoning had been correct; she began to question the logic of expecting her daughter to ask questions about Down syndrome and instead suggested that Sophie's behaviour could communicate more about her awareness of her Down syndrome than she was able to verbalize.

No, just in her behaviour, but I don't know if Sophie can actually turn round and say, say to me, 'mum am I different?' I don't think logically, it wouldn't come like that, it would be more like, I know it annoys her when she starts the shaking or she's turning her head, ...So, verbally, she wouldn't say anything but by her actions, yeah, yeah, definitely by her actions. ...

(Sophie's mother)

In the course of the interview, Abbie's mother also started to reflect on whether Abbie's everyday experience made it inevitable that she would have an awareness of her Down syndrome. This uncertainty made her anxious about the need to broach this topic.

## 4 | DISCUSSION

Families' decisions about what to tell their child about Down syndrome were far from straightforward and some mothers experienced inner conflict about what they should do. At the crux of their struggle was how to deal with the reality that their child was, to a degree, stigmatized by society for having Down syndrome. All mothers were acutely aware that their child was considered different and they believed this information would have a negative impact on their child. Although the mothers felt that they could not avoid addressing this issue with their offspring indefinitely, they were secure in the knowledge that their child's Down syndrome did not define their child in the family context. This view was confirmed by the two parents who had talked to their offspring about Down syndrome. Their exchanges with their offspring about Down syndrome, tended to centre on intellectual impairment or appearance. The social barriers children may face were rarely mentioned and the stigma associated with Down syndrome did not feature at all.

The mothers' approach to addressing the issue of Down syndrome, whether they had done so directly or more subtly, also mirrored that of the parents in Cunningham et al.'s (2000) study. Cunningham et al. (2000) proposed that young people's expressive verbal ability predicted their parents' willingness to talk to their offspring about their Down syndrome, reflecting their parents' sensitivity to their



child's readiness for information. To an extent, this idea fits with the narratives of the mothers in this study, as they all described trying to be responsive to their child's needs. All of the mothers struggled with the tension of wanting to talk to their child openly about Down syndrome and being afraid of saying too much and causing unnecessary hurt. They described waiting for their child to give them a sign to indicate their need or readiness for more in-depth information. However, the mothers' perceptions of their child's ability to understand this information was also informed by their interpretation of complex and sometimes conflicting behavioural signs, alongside what their child said. Ultimately, the mothers were at pains not to let their child know that others might think of them as "different."

Todd and Shearn (1997) also found that parents did not openly discuss their adult offspring's disability to avoid any potential hurt. However, Todd and Shearn (1997) also reported that parents deliberately hid diagnostic labels associated with intellectual disability and the social significance of them from their offspring. Despite being reluctant to talk with their offspring about their Down syndrome, none of the mothers in this study had any intention of hiding the term "Down syndrome."

Part of the tension in the mothers' accounts of how they should support their offspring's developing sense of self was their recognition of the fact that family was only part of their children's lives. The young people were also part of a wider community. Hence, the mothers recognized that there were a number of different influences on their offspring's developing sense of self. This included comparing themselves with other school pupils. Moreover, a number of the mothers recognized the unease their offspring felt when being stared at by others in the street. From the mothers' accounts, being stared at was difficult for the whole family, who experienced a form of "courtesy stigma" (Ali, Hassiotis, Strydon, & King, 2012). The wish to avoid their offspring feeling a sense of difference was a commonly expressed view by all the mothers in the study.

Many of the mothers were very clear that their offspring were aware of their distinctive facial features and how they differed from others. Like the parents in Cunningham et al.'s (2000) study, many of the mothers described occasions when their child had recognized that others with Down syndrome had the same facial features. However, it was interesting that rather than highlighting their difference from non-disabled peers, these individuals were apparently aware of their similarity to others with Down syndrome, or at least they found such awareness easier to demonstrate. Young people were said to respond to this similarity to others with Down syndrome with excitement, perhaps because it was reassuring to see someone that looks like them. Interestingly, none of the mothers made the inference that if their child was able to recognize their similarity to others with Down syndrome, then they were also likely to recognize that they looked different from those without Down syndrome. This also begs the question as to why the children and young people had not asked their parents about why they looked different from others.

It was notable from the interviews that the mothers experienced uncertainty and anxiety regarding the best course of action to take, in relation to talking to their child about Down syndrome.

While mothers feared disclosing too much too soon, they also worried about not disclosing enough to their child. Many mothers commented at the close of the interview that they felt guidance in dealing with their child's developing sense of self as someone with Down syndrome was absent and it was this that, at least in part, motivated them to take part in the study. The mothers' dilemma about how to address this issue perhaps also has to be understood in the broader context of shifting public attitudes to disability. While stigma and broader public prejudice remain, the recognition that people with Down syndrome can lead full lives and make positive contribution to society has grown, with a number of positive high profile campaigns (# leave no one behind; 2019). In this context, mothers of children and young people with Down syndrome have to balance their efforts to promote positive identities and aspirations with an awareness that stigma is still attached to difference and intellectual disability.

Interestingly, in the study by Deakin et al. (2018), the children of the mothers who were interviewed showed an acute awareness of Down syndrome and the associated negative stereotypes. However, Deakin et al. (2018) also found that children and young people with Down syndrome held very positive views about themselves. This is perhaps testament to the role of their families' in ensuring that their children grow up knowing they are loved and valued in their own right, irrespective of how Down syndrome is viewed by society. The young people with Down syndrome may also play their part in this dynamic, by choosing to avoid making their families aware of their knowledge of the negative stereotypes associated with Down syndrome.

This IPA study was carried out with a small sample of mothers and it cannot be assumed that the findings reflect the views of mothers of children with Down syndrome more widely. Furthermore, this study neglected the perspectives of fathers on their child's developing sense of self. Future research would do well to include both parents and perhaps interviewing couples would enable additional insights. A future study that purposefully sampled parents of children with Down syndrome in mainstream and special school might also provide important insight into how wider social factors help to shape their views about their offspring with Down syndrome's developing sense of self. Future research should also perhaps consider how knowledge of negative social attitudes is negotiated between families and their offspring, rather than assuming that children lack insight and families are simply protective. A longitudinal ethnographic approach may provide insight into how children's sense of self emerges from their experiences both inside and outside of the family.

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#### REFERENCES

- Ali, A., Hassiotis, A., Strydon, A., & King, M. (2012). Self-stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities, 33*, 2122–2140. <https://doi.org/10.1016/j.ridd.2012.06.013>

- Crocker, J., Major, B., & Steele, C. (1998). Social stigma. In S. Fiske, D. Gilbert, & G. Lindzey (Eds.), *Handbook of Social Psychology* (pp. 504–553). Boston, MA: McGraw-Hill.
- Cunningham, C. C., Glenn, S., & Fitzpatrick, H. (2000). Parents telling their offspring about down syndrome and disability. *Journal of Applied Research in Intellectual Disabilities*, 13, 47–61. <https://doi.org/10.1046/j.1468-3148.2000.00012.x>
- Deakin, K., Moore, D. G., & Jahoda, A. (2018). Children and young people with down syndrome: Their awareness of down syndrome and developing self-perceptions. *Journal of Applied Research in Intellectual Disabilities, Early View*, 31(6), 1197–1208. <https://doi.org/10.1111/jar.12494>
- Dunn, L. M., Dunn, L. M., & (2009). *The British Picture Vocabulary Scale*. London, UK: GL Assessment Limited.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. England, UK: Penguin.
- Mencap, (2007). *Bullying wrecks lives: The experiences of children and young people with a learning disability*. London, UK: Mencap Publications. Retrieved from <https://www.mencap.org.uk/sites/default/files/2016-07/Bullying%20wrecks%20lives.pdf>
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 8, 20–23.
- Reilly, D. E., Huws, J. C., Hastings, R. P., & Vaughan, F. L. (2008). "When your child dies you don't belong in that world any more"- Experiences of mothers whose child with an intellectual disability has died. *Journal of Applied Research in Intellectual Disabilities*, 21, 546–560. <https://doi.org/10.1111/j.1468-3148.2008.00427.x>
- Saha, S., Doran, E., Osann, K. E., Hom, C., Movsesyan, N., Rosa, D. D., Tournay, A., & Lott, I. T. (2014). Self-concept in children with Down syndrome. *American Journal of Medical Genetics Part A*, 164(8), 1891–1898.
- Scior, K., & Werner, S. (2015). *Changing attitudes to learning disability: A review of the evidence*. London, UK: Mencap.
- Sherman, S. L., Allen, E. G., Bean, L. H., & Freeman, S. B. (2007). Epidemiology of down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 221–227. <https://doi.org/10.1002/mrdd.20157>
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in psychology*, 1(1), 39–54.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Eds.), *Qualitative psychology: A practical guide to methods* (pp. 51–80). London, UK: Sage.
- Todd, S., & Shearn, J. (1997). Family dilemmas and secrets: Parents' disclosure of information to their adult offspring with learning disabilities. *Disability and Society*, 12, 341–366. <https://doi.org/10.1080/09687599727218>

**How to cite this article:** Deakin K, Jahoda A. A supporting role: Mothers' perceptions of their child's developing awareness of Down syndrome. *J Appl Res Intellect Disabil*. 2020;33:1380–1389. <https://doi.org/10.1111/jar.12765>