Perceptions of Down Syndrome in the Australian Community

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Abstract

Community perceptions of Down syndrome were examined in a sample of 1,228 participants. Respondents were asked to complete a rating scale, and report the first thing that came to mind when they thought of Down syndrome. Although the knowledge was reasonably accurate, and the expectations for developmental outcomes were optimistic, there was evidence for stereotyped views. The terms used to describe Down syndrome varied strikingly from very negative to very positive, with significant differences according to age, gender, education, occupation and personal contact. The strength of the data confirmed the potential for this methodology to develop a profound understanding of community attitudes.

Community attitudes are important determinants of the acceptance and support people with Down syndrome receive and of the opportunities that are available to them within their communities. Misconceptions about the behaviour, personalities and developmental potential of people with disabilities are likely to create negative attitudes and subsequent reactions such as discomfort, rejection or pity (Gouvier & Coon, 2002; Krahé & Altwasser, 2006; McCaughey & Strohmer, 2005).

Although various researchers have investigated the attitudes towards people with disabilities, including Down syndrome, most of the research has been conducted with specific respondent groups, such as undergraduate students or special education teachers (see Duvdevany, Rimmerman & Portowicz, 1995; Gregory, 1997; Hastings, Sjőstrőm & Stevenage, 1998; Horner-Johnson, Keys, Henry, Yamaki & Oi, 2002; Wilson & Mazzocco, 1993; Wishart & Manning, 1996). The views of these groups, however, are unlikely to represent the views of the general community. Members of these groups generally have higher levels of education and, in some cases, specific training in disability. Research with community samples has reported reasonably accurate knowledge of various disabilities (Roth & Smith, 1983), including Down syndrome (Gilmore, Campbell & Cuskelly, 2003). However, the attitudes towards inclusive practices held by the general community are less positive than those held by teachers and university students (Gilmore et al., 2003; Yazbeck, McVily & Parmenter, 2004).

Several authors have criticized the tendency for researchers to rely on self-report rating scales to measure attitudes towards people with disabilities. For instance, Daruwalla (cited in Daruwalla & Darcy, 2005) suggested that the favourable attitudes, verbalized within the general community, often mask deeper feelings that lead to rejection of persons with disabilities. Indeed, traditional self-report questionnaires are susceptible to various response biases, including the tendency of respondents to present themselves in ways that they perceive to be socially or politically correct (Akrami, Ekehammar & Claesson, (2006)).

Alternatives to self-report rating scales include naturalistic measurements of attitudes (see Kastner, Reppucci & Pezzoli, 1979; Robertson et al., 2005), and methods that involve inviting participants to comment on specific disabilities without the prompting that is usually provided by rating scales. Using the latter methodology, McCaughey and Strohmer (2005) asked undergraduate psychology students to list 10 features they associated with each of 6 different disabilities in order to develop "prototypes" or cognitive representations of disability. Their responses revealed some common misconceptions, such as the belief that people with intellectual disabilities are happy, loving, and dependent on others. Whilst this methodology offers promising results in research on perceptions of disability, the task used by McCaughey and Strohmer is more suited to a university classroom than to the general community.

In addition to focusing on cognitive representations of disability, it is important to tap into the affective component of attitudes as well, because emotional reactions may be the source of the negative responses to persons with disabilities. Identifying both cognitive and affective components may be achieved by asking for spontaneous responses that are not prompted or constrained in any way. The goal of the present study was to make a methodological contribution to the study of attitudes towards people with disabilities and to extend the limited data about attitudes within the general community. Specifically, the project investigated community perceptions of Down syndrome by asking participants to report the first thing that came to mind when they thought of Down syndrome, followed by a series of questions in rating scale format.

Method

Participants

The participants, 1,228 members of the Australian community, mostly resided in South-East Queensland. The sample was reasonably representative of the Australian population in relation to occupation, but somewhat less for education (see Table 1). Within the sample, 44% of females and 34% of males reported that they knew a person with Down syndrome, and older people were more likely to have some personal knowledge (e.g., 35% of 20-29 year olds compared to 46% of those over 50 years).

Table 1. Descriptive characteristics of the sample: Age, education and occupation

	Age					*Highest Education Completed*			*Occupation* [a]		
	20-29	30-39	40-49	50-59	60+	High school	Diploma/ certificate	Tertiary study	Group 1	Group 2	Group 3
Female (*n* = 646)	31%	22%	21%	18%	8%	36%	21%	43%	50%	35%	15%
Male (*n* = 582)	35%	22%	16%	18%	9%	36%	25%	39%	52%	30%	18%
Total Sample (*n* = 1228)	33%	22%	19%	18%	8%	36%	23%	41%	51%	33%	16%
						49% [b]	31% [b]	20% [b]	40% [b]	33% [b]	27% [b]

[a] *Occupation is presented in this table using the method of condensing the ASCO (Australian Standard Classification of Occupations) categories proposed by Najman and Bampton (1991). Group 1 = managerial, professional and para-professional, Group 2 = tradespersons, advanced and intermediate clerical, sales and service workers, and Group 3 = production and transport workers, elementary clerical, sales and service workers*

[b] *ABS (2005) figures for the Australian population*

Measure

The questionnaire contained two parts. The first part consisted of a single open-ended question ("What is the first thing that comes to mind when you think about Down syndrome?") The second section was adapted from instruments used previously by Wishart and Manning (1996) and Gilmore et al. (2003) to assess knowledge of Down syndrome and attitudes towards inclusive education. It contained questions about the causes of Down syndrome, features associated with the syndrome, developmental expectations for children and adults, and optimal school and adult living options for individuals with the syndrome.

Procedure

The questionnaires were administered by first year students enrolled in a teacher training degree at a large Australian university. Each student contacted 6-8 members of the community (3-4 male and 3-4 female) and administered the questionnaire following a strict protocol of directions. Responses to the first question were transcribed verbatim. The remaining questions were completed immediately afterwards, either with the student researcher or independently by the respondent. University ethical clearance was obtained to use questionnaires for research purposes in cases where both the respondent and the student researcher gave consent.

Results

Rating scale responses

Responses to the rating scale items showed the participants had reasonably accurate knowledge about Down syndrome. Over 86% of the sample recognized that Down syndrome resulted from a chromosome disorder, and very few respondents believed that factors such as physical injury (2.5%), adverse responses to substances (6%), and emotional trauma (2.5%), were implicated causally.

Developmental expectations were positive and optimistic. For instance, 41% of the respondents thought it was likely that a child with Down syndrome could follow school rules and participate in most school activities. In most school activities and 40% thought this level of engagement was possible. The achievement of basic literacy and numeracy was rated as at least possible by 86% of respondents.

All but 12% of the respondents believed that independent living skills such as shopping, cooking, and using public transport were possible, likely, or very likely attainable by adults with Down syndrome. Similarly, working independently at a job was rated as possible (43%), likely (29%) or very likely (11%), with only 17% of the sample seeing paid work as an unlikely activity in adult life.

The views on peer relationships in childhood and intimate relationships in adulthood were positive. Almost 40% of respondents believed that children with Down syndrome were likely, or very likely, to develop and maintain good relationships with their peers. Another 40% believed friendships were possible. For adults with Down syndrome, the maintenance of long-term intimate relationships was considered to be very likely (11%), likely (29%) or at least possible (42%) to achieve.

Despite such optimistic predictions about outcomes, 26% of the sample regarded special schools as the best educational setting for a child with Down syndrome, and 48% chose an option that combined both special and regular schooling. Only 25% of respondents believed the regular classroom, with support if necessary, was the best option. When asked about the best living arrangements for an adult with Down syndrome, 26% chose the family home; 45% nominated a shared group house; and 27% selected an independent home. Very few respondents (only 2% of the sample) advocated institutional living for adults with Down syndrome.

Respondents were asked to consider how children with Down syndrome differed from children developing without Down syndrome on a range of individual characteristics. Significant proportions of the sample reported that children with Down syndrome were less intelligent (70%), less physically attractive (76%) and more affectionate (67%) than their typically developing peers. Only 1% of respondents stated that children with Down syndrome were more physically attractive, and only 4% said they were less affectionate. Almost half of the respondents (48%) felt that children with Down syndrome were happier than other children and very few (4%) believed they were less happy.

Responses to the initial open-ended question

Responses to the first question (What is the first thing that comes to mind when you think about Down syndrome?) were coded using categories developed from the data. In cases where a response involved more than one category, only the first was coded.

Many participants spontaneously identified features of Down syndrome, such as physical anomalies (34%), intellectual disability (10%) and chromosome abnormality (8%). The stereotype that individuals with Down syndrome are characterized as affectionate, happy, and smiling, was clearly evident in these unprompted responses. For 20% of the sample, the affectionate, loving image was the first thing that came to mind. Notable differences were apparent in the responses depending on gender or knowledge of someone with Down syndrome (see Table 2). Males were significantly more likely to mention intellectual impairment ($\chi 2$ (1) = 4.521, $p <. 05$), while females commented more frequently on affectionate personalities ($\chi 2$ (1) = 31.66, $p < .001$). Respondents with some affiliation or knowledge of a person with Down syndrome were significantly more likely to mention affectionate natures ($\chi 2$ (1) = 12.47 (1), $p < .01$). Those without previous personal knowledge were more likely to note physical appearance ($\chi 2$ (1) = 5.85, $p < .05$).

Table 2. Percentages of each group giving responses within the different categories for the question, "What is the first thing that comes to mind when you think of Down syndrome?"

Category of response	*Total group*	*Female*	*Male*	*Personal knowledge*	*No personal knowledge*
Physical appearance	34	32	37	31	37
Affectionate loving nature	20	26	13	25	16
Intellectual impairment	10	8	12	10	10
Chromosome disorder	8	9	7	8	8
Burden for parents	6	6	6	6	6
Various difficulties (e.g. behaviour)	2	2	2	1	2
Familiar person	3	3	4	6	2
Labels/names (e.g. Mongol)	2	1	3	2	2
Other (e.g. health, special school)	9	8	10	7	11
No response	6	5	6	4	6
Total	100	100	100	100	100

Striking differences were noted in the terms used to describe Down syndrome. Some responses were phrased positively, and other responses were more negatively expressed. For instance, the distinctive facial features associated with Down syndrome were described as *unique, special, cute* or *cheeky* by some participants. Others participants used terms like *deformed, disfigured, distorted, peculiar* or *funny*. The answers of almost 10% of the sample contained particularly negative expressions, including sympathy or pity *(poor bastard, I feel so sorry for them, what a shame)*; references to a person with Down syndrome as being dependent, unfortunate or child-like *(trapped in the mind of a child)*; comments about family hardship and grief *(horror for parents, burden for life)*; the extreme impact of the condition *(terrible condition, severely debilitating, it's bad)*; or relief at not having Down syndrome children of their own *(thank God I'm lucky enough to have healthy children)*. For a few respondents, derogatory labels such as *mongoloid, spastic,* or *potato head* came immediately to mind. However, around 21% of the sample commented more positively and sensitively using words like *bubbly, gentle, sociable, cuddly, mischievous* and *bouncy*. Individuals with Down syndrome were described as *the kindest people ever* and *so generous, quiet loving people* and *the most delightful friendly children.*

Analyses of within-group differences showed that positive comments were made more frequently by females ($\chi2$ (1) = 18.11, $p < .001$) and those with personal knowledge of someone with Down syndrome ($\chi2$ (1) = 8.96, $p < .01$). There were also significant differences according to age ($\chi2$ (4) = 27.74, $p < .001$), education ($\chi2$ (4) = 18.24, $p < .001$) and occupation ($\chi2$ (8) = 34.02, $p < .001$). Younger people, more educated people, and managers/professionals/trades people made fewer positive comments. For instance, 32% of participants in the 50-59 age group commented positively, while only 14% of the 20-29 year olds did the same; and 31% of respondents with junior high school education commented positively compared with 16% of those with tertiary qualifications. Positive statements were made less frequently by managers (12%), professionals (13%) and trades people (10%) than by other occupational groupings (25% to 35%).

Discussion

The results of this study confirm some of the previous findings about community attitudes towards people with disabilities including Down syndrome. The inclusion of a question to elicit spontaneous responses has produced valuable insights into the ways in which Down syndrome is perceived within the general community. In particular, responses illustrate the emotional, as well as, the cognitive components of attitudes towards people with disabilities.

It seems clear that most people have a reasonably accurate knowledge about the causes and consequences of Down syndrome. The majority of people know that this disorder is due to a chromosome abnormality (Selikowitz, 1997), that results in intellectual impairment (Carr, 1995) and produces a distinctive physical appearance (Cunningham, Turner, Sloper & Knussen, 1991). The characteristic facial features make Down syndrome a very visible and easily recognizable disorder within the community. In this sample the physical appearance of those with Down syndrome was often evaluated negatively (e.g., *ugly, dumpy, recessed eyes, pokey-out ears, bad basin haircuts)*, suggesting stigma and stereotyping, and the majority of respondents reported that children with Down syndrome are less physically attractive than their typical peers.

A tendency to presume that people with Down syndrome share not only similar physical appearances, but also similar characteristics of temperament and behaviour (e.g., *"they all look the same and act the same"*) was also apparent. This misconception fails to recognize the considerable variation amongst individuals with Down syndrome, reflecting a 'myth of uniformity' which has no basis in fact (Hayes, 1990). Although, Down syndrome is associated with a distinctive pattern of developmental delay, cognitive impairment, sensory deficits and medical problems (Selikowitz, 1997; Stratford & Gunn, 1996) a single individual usually displays only 10 to 12 of the more than a hundred different characteristics associated with the syndrome (Hayes, 1990).

The well-established stereotype of affectionate loving personalities was particularly evident in this sample, reinforcing previous findings for Down syndrome (Gilmore et al., 2003) and intellectual disability more generally (McCaughey & Strohmer, 2005). Contrary to these beliefs, not all children with Down syndrome are happy and sociable (Pary, 2004). In general, they display the same range of personality characteristics as children who are developing typically (Chapman & Hesketh, 2000; Gunn & Cuskelly, 1991; Robison, 2000; Vaughn, Contreras & Seifer, 1994).

Many children with Down syndrome are now educated in regular classrooms and fewer adults live in institutions (Nadel & Rosenthal, 1995). Although views about regular schooling were not very positive in this community sample, developmental expectations were relatively high. For instance, most people recognized that children with Down syndrome develop friendships with their peers (Freeman, 1998; Laws, Taylor, Bennie & Buckley, 1996) and achieve at least basic levels of literacy (Boudreau, 2002). Views about adult attainments tended to be overly optimistic with many respondents appearing not to recognize the impact of intellectual impairment on adaptive functioning. Goals such as long-term intimate relationships and independent employment were often regarded as likely or very likely to be achieved. Yet, marriage for persons with Down syndrome is still an unusual occurrence (Marcus, 2005) and, while supported employment is a reasonable expectation (Nadel & Rosenthal, 1995), working independently for pay is not likely.

Although the majority of all respondents mentioned physical appearance as the first thing that came to mind, females were more likely than males to mention personal characteristics such as affectionate, happy and friendly natures, while males focused more on intellectual disability. Similarly, those with personal knowledge of someone with Down syndrome were more likely to focus on positive personality traits than those with no personal knowledge who focused more on superficial appearances. It is not surprising that knowing someone with Down syndrome lets people see beyond superficial physical appearances to the personal characteristics of the individual. The association of personal contact with more positive attitudes has been consistently demonstrated (e.g., Daruwalla & Darcy, 2005; Yazbeck et al., 2004).

Previous findings about the relationships of participant gender, age and education with attitudes have been mixed although, contrary to the current findings, most studies have reported more positive attitudes in younger people and those with higher levels of education. Given that the research participants are often young university students or professionals and that varying methodologies have been used, it is not surprising that findings of within-group differences are inconsistent. It is possible that the spontaneous responses analyzed in the current study are reflecting deeply embedded emotional reactions to disability that have not previously been tapped by traditional rating scales.

In summary, several misconceptions about Down syndrome are apparent in this community sample – the belief that all people with Down syndrome are the same, the personality stereotype of affectionate happy individuals, and the overly optimistic views about adult attainments. While positive stereotypes might be seen as acceptable and desirable, such misconceptions have the potential to be damaging when they lead to unrealistic expectations and a failure to recognize the uniqueness of each individual with Down syndrome. Although overly positive comments may be preferable to overly negative ones, perceptions of Down syndrome that are both optimistic and realistic will lead to more appropriate understanding and support for persons with Down syndrome within the community.

The present study has several limitations. The fact that respondents were known personally to their student interviewers may have biased the responses towards more socially acceptable ones. Given the key role that personal contact reportedly has in promoting positive attitudes (Robertson et al., 2005), it may have been useful to distinguish the level of contact that participants had experienced with a person with Down syndrome. In addition, the use of more than one open-ended question might have provided additional useful information.

Data from large community samples are difficult and costly to obtain. Yazbeck et al. (2004), for instance, were able to include only 127 respondents from the community in their study of attitudes. Obtaining data that is representative of the population in terms of education and occupation presents an additional challenge. Nevertheless, given the importance of community attitudes for the acceptance and support that are offered to people with disabilities, it is vital that researchers continue to gather data from community samples and that attempts are made to establish new methodologies for developing a deeper understanding of the various components of attitudes.

Perhaps we will then better understand the basis for community perceptions of Down syndrome, so that we can develop ways of turning negative first impressions of *mongols with a particular look in their staring type eyes* into more positive thoughts of *lovable, caring people ... trying to interact with the world around them.*

Acknowledgements

The author would like to thank the students and tutors who assisted in collecting the data for this project, as well as Anne Hodgkiss, Celia Whitton and Robyn Ward for their enthusiastic commitment to data entry. Monica Cuskelly and Jenny Campbell provided thoughtful and encouraging comments on an earlier draft of this paper.

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