The Perspective and Experience of Families Raising a Child with Williams Syndrome

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Abstract

Sharing a diagnosis of a developmental disability with parents is not an easy task for clinicians and many parents report frustration and dissatisfaction with the information they receive. This is particularly pertinent for families of children with less common developmental disabilities. The current study employed a qualitative methodology to investigate the experience of parents, siblings, and grandparents raising a child with Williams syndrome or Down syndrome with the objective of making balanced information available to families starting out on their journey. The current study indicates that parents of children with Williams syndrome seek similar kinds of information to parents of children with Down syndrome. Therefore, guidelines which exist to aid clinicians in providing information to families of children with Down syndrome may also be appropriate for use in families of children with Williams syndrome.

The Perspective and Experience of Families Raising a Child With Williams Syndrome

Sharing a diagnosis of a developmental disability with parents is not an easy task for clinicians and many parents report frustration and dissatisfaction with the information they receive (Skotko & Bedia, 2005; Waxler, Cherniske, Dieter, Herd & Pober, 2012). Dent and Carey (2006) reviewed the literature evaluating delivery of difficult news in a newborn setting and report that sharing diagnoses in a sensitive, caring, and confident manner supports parents in adjusting to and accepting a diagnosis. Unfortunately, clinicians tasked with sharing such diagnoses often have little training in how to do so (Dent & Carey, 2006), and tend to favour a focus on clinical information (clinical complications and antagonistic aspects of the condition) above more positive information (treatment, abilities, management, and improved life expectancy) (Sheets, Best, Brasington & Will, 2011). In contrast, parents describe desiring a positive, confident, and informative discussion with appropriate referral to support groups (Dent & Carey, 2006).

Down Syndrome: A Model Developmental Syndrome

In response to calls for change from parents, the evidence-based guidelines and the national consensus statement (American College of Obstetricians and Gynaecologists, 2009) indicate that when providing information to new or expectant parents of children with Down syndrome (DS), clinicians should provide up-to-date, accurate, and complete information about DS (Skotko, Levine & Goldstein, 2011). Similarly, evidence-based reviews by the Down Syndrome Diagnosis Study Group suggest that new and expectant parents receive accurate information in practical terms about the nature and causes of DS and what it means to live with DS in society today (Skotko, Capone & Kishnani, 2009). Moreover, literature investigating the experience of families receiving a diagnosis of DS reveal that new and expectant parents particularly value information that illustrates what life is like for a child with DS; the abilities and potential of people with DS; and positive examples of outcomes for

individuals with DS (Skotko et al., 2011). Unfortunately, there is a dearth of studies investigating the experience or informational needs of families raising children with less common genetic disorders.

Williams Syndrome

Williams syndrome (WS) is a rare genetic neurodevelopmental disorder with a prevalence of 1: 7 500 births (Stromme, Bjornstad & Ramstad, 2002). It is associated with characteristic facial features; heart and connective tissue defects; and mild to moderate intellectual disability (Hocking, Bradshaw & Rinehart, 2008; Mervis & Robinson, 2000). Individuals with WS are described as overly friendly, gregarious, empathic, with a profile of indiscriminate social drive or "hyper sociability", but with difficulties in interpreting social cues and norms, alongside increased attention deficits, distractibility, and non-social anxiety (Morris, 2010). While research has tended to focus on the phenotypic personality profile of children with WS, there is an absence of literature investigating the experience of families raising these children. Such research is needed to provide information to families with a new diagnosis of WS about what family life may look like.

Waxler, Cherniske, Dieter, Herd and Pober (2012) investigated parent's experience of receiving a diagnosis of WS for their child. Six hundred families in America participated and 60% reported negative recollections about the experience, and half of those denied recalling anything positive at all. Factors which were associated with a more positive experience included receiving written information about WS, and receiving genetic counselling. Genetic counselling aims to promote understanding of genetic conditions, informed decision-making, adjustment to diagnosis, and emotional support (Sheets, Best, Brasington & Will, 2011). Additionally, one quarter of participants expressed a desire to be given hope when receiving the diagnosis. This study indicates that parents receiving a new diagnosis of WS for their child are dissatisfied with the information they are receiving, and are calling for more

balanced information about the rewards and challenges of raising these children. It is plausible that parents of children with WS are desiring similar types of information as parents of children with DS. As such, guidelines which exist to aid clinicians in providing diagnoses of DS may also be helpful in guiding delivery of a diagnosis of WS.

Similarities and Differences Between Williams Syndrome and Down Syndrome

A review of the literature by Hodapp, Ly, Fidler and Ricci (2001) reveals that while specific genetic disorders predispose children to different etiologic behaviours, WS shares some overlap with DS. Both syndromes are associated with mild to moderate intellectual disability; various health complications (i.e. heart defects); and positive personality characteristics. For example, the literature has reported a "Down syndrome advantage" whereby children with DS are described as more social with less maladaptive behaviours than children with other neurodevelopmental disorders (Esbensen & Seltzer, 2011). Importantly, research has shown that maladaptive behaviour constitutes the single best predictor of parental stress (Dabrowska & Picola, 2010; Hayes & Watson, 2012). Concurrently, research has demonstrated that children with WS are clearly distinguishable from children with other neurodevelopmental disorders based on specific personality attributes such as extraversion, gregariousness, empathy, trust, and sensitivity (Klein-Tasman & Mervis, 2003). Fidler, Hodapp and Dykens (2000) report that although children with WS typically demonstrate more maladaptive behaviours than children with DS, their parents do not report more parenting stress. Fidler et al. suggest that the phenotypic personality characteristics associated with WS such as sociability and empathy, buffer parenting stress. Taken together, similarities in the perspective and experiences of families raising a child with WS or DS may be plausible.

Research Aims and Objectives

There is a dearth of literature investigating the experience of families raising a child with WS, and a recent investigation by Waxler, Cherniske, Dieter, Herd and Pober (2012) indicates that families receiving a diagnosis of WS for their child are dissatisfied with the information they receive. Therefore, the current study had three aims. The first was to investigate rewards and challenges reported by families raising a child with WS with the objective to make balanced information available to new parents. The second aim was to investigate similarities in the rewards and challenges between families raising a child with DS versus WS. The third aim was to investigate parent's experience of receiving a diagnosis of WS for their child. The objective of the second and third aims was to consider the possible use of existing DS guidelines for supporting clinicians in providing diagnoses of WS.

Method

Participants

Parents, grandparents, and siblings of individuals with DS and WS were invited to complete an online Qualtrics survey about their experience raising a family member with a neurodevelopmental disorder.

Thirteen family members of individuals with DS were recruited via an advertisement in the Down Syndrome Australia Newsletter. Of the participants, 13 were female and included 11 mothers, one grandmother, 1 sister. The age range of the individuals' with DS ranged from one year to 23 years of age. The mean age of the individuals with DS was 10 years and included six males and seven females.

Ten family members (two fathers, seven mothers, and one sister) of individuals with WS were recruited via the Williams syndrome Family Support Group (Victoria, Queensland, and Western Australia) Facebook Pages. The age range of the individuals with WS ranged from two years of age to 43 years . The mean age of the individuals with WS was 18 years and included four males and six females.

Materials and Procedure

The Australian Catholic University Human Research Ethics Committee granted ethical approval for the study. Participants accessed the survey via a hyperlink and were prompted to provide informed consent; demographic details; and written responses to ten open-ended questions. The questionnaire was adapted from King, Zwaigenbaum, Baxter and Rosenbaum (2009) and was designed to assess the experience and perspectives of family members of an individual with WS or DS. (See Appendix A). Participants were invited to provide written responses.

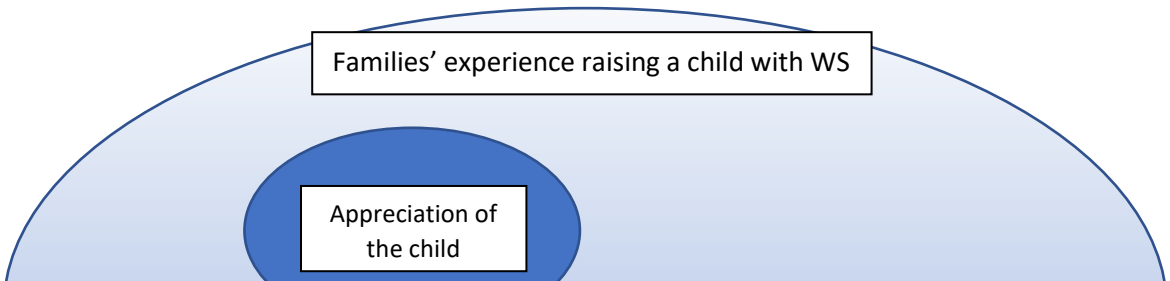
The WS group was sent a follow up questionnaire assessing the impact of receiving the diagnosis of Williams syndrome for their child. Questions were adapted from Waxler, Cherniske, Dieter, Herd and Pober (2012). (See Appendix B). Participants were invited to provide written responses.

Data analysis

Thematic analysis was undertaken using the method described by Braun and Clarke (2006). Responses were coded and analysed using a grounded theory approach (Crewsell, 1994) whereby an open coding process was used to identify naturally occurring concept categories in the data. Themes emerged through an inductive process and concept categories were created that explained the data. Statements were coded according to their key concepts and coded concepts were clustered into themes.

Results

Similarities and differences emerged between groups raising a child with DS or WS. Figure 1 illustrates the major themes and the relationships between themes in each group. The size of the circles that encompass each major theme represent the number of instances the theme emerged in the data (as per Povee, Roberts, Bourke & Leonard, 2012).



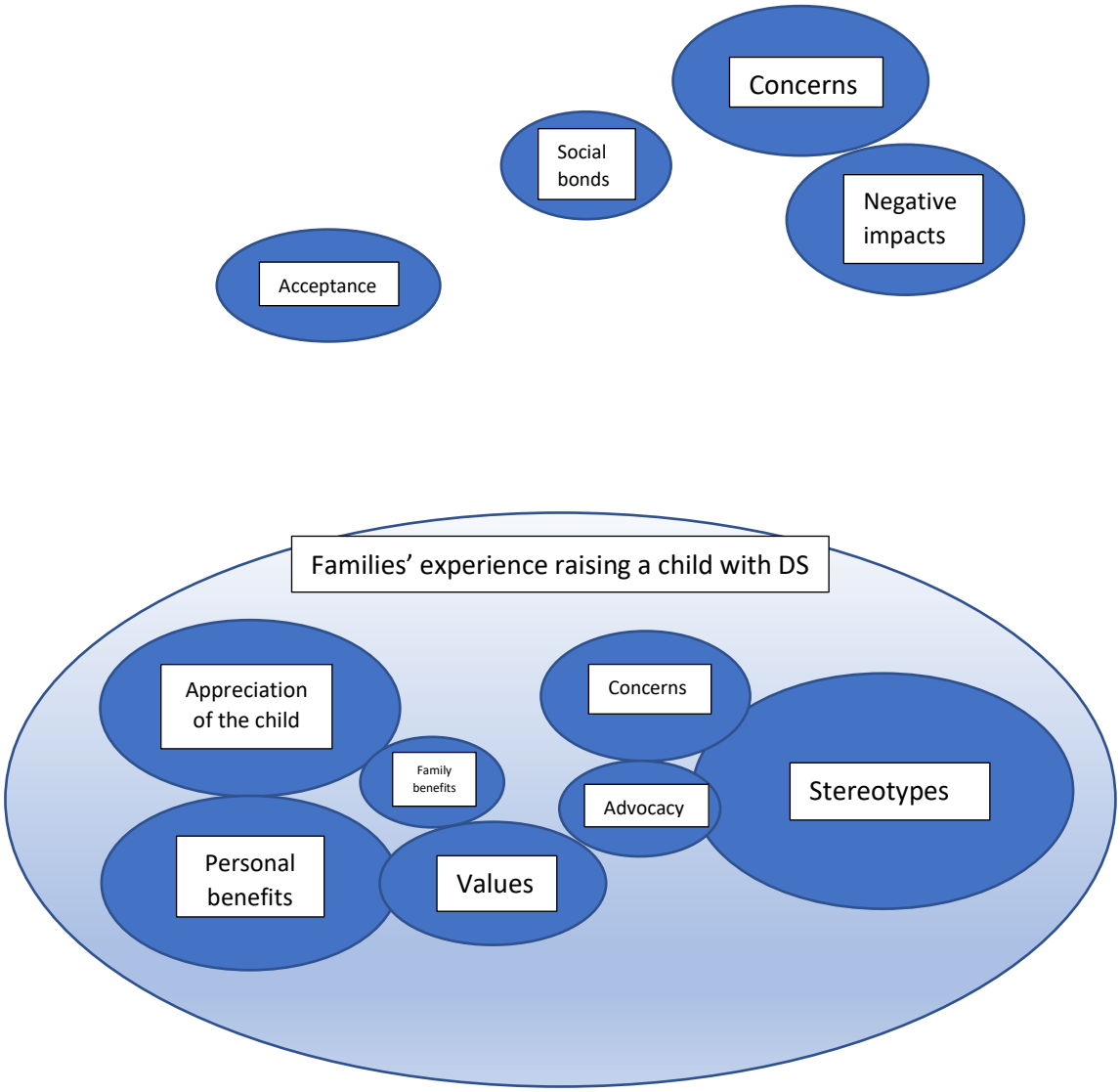


Figure 1. Schematic illustration of themes reported by families raising a child with WS or DS

Group similarities

Appreciation of the child and family benefits.

Both groups reported similar levels of appreciation and family benefits experienced by raising a child with WS or DS. Families raising a child with DS described them as joyful, caring, loyal family members*: "I appreciate her sense of humour. Her ability to see things from a different perspective"* (P11,DS). Another mother reported that raising a child with DS

"*has brought characteristics and strengths out of each of our family members, that I know would have laid dormant forever without having the privilege of having our son"* (P5,DS).

Families raising a child with WS typically appreciated their family member's happy disposition and caring nature. One mother reflected that *"My life is richer because of him, he is intuitive and can always make me feel better as he knows when to give me a hug if I'm feeling down. We are proud of who he has become"* (P4,WS). Another parent reflected that: "*I often think that she has all of the best attributes of each of us all melded into one person"* (P1,WS). One father highlighted benefits to siblings: "*Our other two children have learned empathy and care at a much younger age than norma*l" (P5,WS).

Personal benefits.

Both groups described personal benefits of having a family member with a disability. Several participants described feeling a greater sense of purpose, joy, and open mindedness*: "It has been the most rewarding, beautiful aspect of my life. It has given me a greater life purpose and joy I had never imagined possible*" (P8,DS). Personal benefits were also reported by siblings in both groups: "*I am studying to be a primary school teacher then plan to go onto specialised (sic) in special needs. I don't think I would have had the drive that I do without him. I feel that I would not have been brought up that way without having a brother with DS"* (P13,DS). Similarly*"In a way I think having a sister with a disability made me a better person, I am more aware of the things I say and how it affects people. I love (her) for who she is and wouldn't change her for the world"* (P3,WS). Participants in both groups described having developed a more open mind and more tolerance for other people.

Values.

Both groups reported that raising a family member with a disability had altered their values, worldview, or priorities over time. Participants described becoming less competitive and developing more empathy for people as a consequence of having a family member with a

disability. *"I think we have changed our views of success. Instead of winning prizes, it is about being the best that you can be"* (P2,WS). However, greater emphasis on values derived from having a family member with a disability was reported by the DS group. They described family values around equality, inclusion, patience, kindness and helping others: "*we think about different ways for everyone to be able to participate in activities. We learnt to be happy at the slower achievement of milestones (appreciate the journey). We learnt tolerance and to help each other"* (P11,DS). Closely related to values in the DS group was the concept of advocating for their family member (in social, educational, and medical settings). In contrast, the WS group spoke frequently about acceptance.

Concerns.

Both groups had concerns about the vulnerability of their family member with WS or DS and worried about what would happen to them when they (the parents) pass away. *"She needs to have someone with her when we even go for a walk around the block as she is likely to get lost or talk to stranger even though she has walked around the same block hundreds of times and we have had lots of "stranger danger" talks. She is unable to tell whether she has the correct change or to manage her finances at all"* (P1,WS). *"I am concerned that my daughter has a very high chance of sexual and physical abuse, particularly when my husband and I pass away"* (P6,DS). Vulnerability concerns raised by the WS group were often related to their family member's prosocial, trusting disposition, which paired with their intellectual disability, makes them vulnerable to exploitation. In comparison, the DS group more frequently described concerns about the negative stereotypes associated with DS and intellectual disability.

Both groups listed many concerns around planning for the future, especially around support and engagement for their family member. Parents in the DS group reported having to adopt strong advocate roles for their family member with a disability and described having to

"*jump through hoops*" (P3,DS) to access educational, medical, employment and housing support for their family member. Family members of persons with WS shared concerns about pathways after high school and living arrangements for the future: *"our WS girl has 1 1/2 years of school left so we are concerned about what the next step is for her…. I am unsure whether she will do a TAFE course, a private course, or begin volunteering. I think it is very unfair that people with disabilities are on a lesser wage than others and that mainstream work options are limited. There are very few disability services in the animal care industry and it is unfair that my child may need to be slotted into a disability service in an industry she may not be interested in"* (P1,WS).

Both groups also highlighted loneliness, isolation, and a lack of support as challenges encountered raising a family member with a disability: *"It is a rollercoaster ride supporting her, and I find it difficult to cope with. I feel a lot of responsibility rests on my shoulders"* (P2,WS).

Group differences:

Stereotypes

The strongest theme to emerge, and unique to the DS group, was the concept of stereotypes. Succinctly highlighting this theme: *"Each person is different and affected by disability differently but is still shamefully painted the same"* (P3,DS). Many commented that their family member is more than just a diagnosis and complained that service providers often have pre-conceived ideas about supporting their family member rather than addressing their individual needs: *"I have found that health care professionals don't listen to me when discussing my daughter. They seem to just treat her as her diagnosis. Hypotonia is common in those with DS so she must have it, when she doesn't. It is very frustrating as she then receives support for these 'preconceived' ideas about her diagnosis when she needs help in other areas"* (P3,DS). Many families also cited discrimination: "*My daughter does not*

appear to have equal rights to that of a "normal" child" (P12,DS). Threaded throughout responses from participants were appeals for disability to be normalised and accepted, and for their family members to be valued and fully included in society.

Negative impacts

Work and career adjustments were highlighted by WS family members: "*It has impacted on my work/career choices greatly. I now work part-time as an aide, a job I'm sure I never would have considered if I hadn't had a child with a disability. I work part time so that I can be available 'after school' even though my child is well past school age"* (P2,WS). Several parents described compromises they had made to accommodate their child's needs such as reduced working hours and adjusted career pathways. Other impacts were also highlighted such as: "*extra day to day challenges as we make sure she has her clothes on the right way around, she has her bra done up correctly, she has deodorant on and she does need help to do things like wash her hair and brush her teeth"* (P1,WS). And*: "It affects many day-to-day decisions about how our family operates to other decisions about where we holiday. She is a fussy eater so our food choices are always influenced by what she will eat"* (P2,WS). One mother of an adult person with WS commented: *"I feel that our WS people are a real challenge especially as they grow older and become somewhat intolerant and grumpy and are no longer the cute, delightful little people that they were"* (P6,WS).

Social bonds

The WS group highlighted the social bonds formed by their family member with WS: "*He relates well to everyone, he can be with the adults and talking footy one minute talking music with the young adults the next and then sitting watching cartoons with the kids laughing along with everyone. He is such a loved and integral part of all our extended family"* (P4,WS). Similarly: *"She makes connections with people and they respond to her spirit. Her friends at her 21st ranged in age from peers to neighbourhood friends in their 70s*

and 80s" (P2,WS). Several families also commented on the social support connections they had made because of having a child with WS*: "It is because of her that I have met the most amazing people with WS and their families as well as other families with children with a wide variety of disabilities. These people are the most extraordinary and yet so down to earth people you could ever meet and I feel humbled for having had the chance to get to know them and call them my (our) friends"* (P1,WS).

Acceptance

Finally, the concept of 'acceptance' emerged from the responses of family members of persons with WS. Family members made several comments that reflected their adjustment to their child's disability, and acceptance of their child for who they are: *"I then stopped comparing her to our friend's (mainstream) children and realised that she was who she was and learned to enjoy her for being her beautiful, funny, happy self. I have true acceptance of people with disabilities and am very lucky to be a Mum of such an extraordinary girl. She is so funny, she makes us laugh every day and we would not have her any other way"* (P1,WS). Similarly: *"She will always be (herself), no one else! Which is why I was never shocked or upset about her diagnosis"* (P5,WS). One sibling also described how having a family member with a disability had taught her friends and family to be more accepting of people with disabilities (P3,WS).

The impact of receiving the diagnosis of Williams syndrome in their child

The data revealed that parents who received the diagnosis within the last five years generally reported feeling more satisfied with the information they received, compared with families who received the diagnosis more than 15 years ago.

There were several factors associated with reporting a more positive experience. These included: 1) Talking with a clinician who is informed about WS and who can provide support and information with the diagnosis: *"He was very nice and understanding and gave*

us heaps of information about WS. And an amazing diagnosis letter to help get our son the interventions he needs" (P7,WS); 2) Transparent and timely communication from clinicians about their suspicions; 3) Receiving printed information about WS; 4) Receiving information about social media and community family support groups; 5) Hearing positive affirmations about their child i.e. "*That our son will be a remarkable loving soul"* (P7,WS)*;* 6) Receiving prompt referrals to access early intervention; and 7) Contacting family support groups soon after diagnosis. *"We made contact with a support group quite soon after diagnosis and that was helpful"* (P2,WS).

Families also made suggestions about information that, in hindsight, would have been helpful to receive: 1) Support and advice post-diagnosis; 2) Up-to-date information; 3) An empathic, supportive, informed approach; and 4) An information package to take away and digest after the diagnosis: *"I think there needs to be a couple of people present when diagnosis is issued and a counsellor present for immediate support and ongoing support. Information folder needs to be given immediately to take home to peruse at your leisure with contact names and numbers of support groups, Facebook pages, forums etc"* (P6,WS).

Parents described factors which were unhelpful, or insensitive at the time of diagnosis: 1) Clinicians who are unprepared and uninformed about the condition: *"The Paed in our area seems uninterested and we have to press him for information. He does not seem to be prepared for us when we visit"* (P8,WS); 2) Information that is out-of-date; 3) Diagnosis delivered without reassurance; 4) Being told that support groups are unhelpful; 5) Hearing the clinician talk about their child as an 'interesting condition' as opposed to a person: *"Saying an MRI of his brain would be interesting to see, we felt as if he was using our son as an experiment"* (P9,WS); and 6) Being told diagnoses-related information over the phone.

Discussion

The aims of the present study were threefold: To investigate rewards and challenges reported by families raising a child with WS; to investigate similarities in the rewards and challenges between families raising a child with DS versus WS; and to investigate parent's experience of receiving a diagnosis of WS for their child. The objectives were to make balanced information available to parents receiving a new diagnosis of WS, and to explore the possibility that existing guidelines for providing diagnoses of DS may be useful to support clinicians in providing diagnoses of WS.

The data revealed many similarities in themes reported by families raising a child with WS or DS. The most common theme reported by the WS group, which was equally common among the DS group, was appreciation of the individual with a disability.

Likewise, both groups described several personal benefits to having a family member with a disability, although these benefits were more frequently cited in the (larger) DS group. This is congruent with research which has described a "Down syndrome advantage" which highlights the behavioural phonotype of DS as associated with less maladaptive behaviours and parenting stress (Dabrowska & Pisula, 2010; Esbensen & Seltzer, 2011; Hayes & Watson, 2012). Consistent with previous research (King, Zwaigenbaum, Baxter, & Rosenbaum, 2011; Skotko & Levine, 2006) siblings reflected that being raised with a brother or sister with a disability had helped them to be 'better people'. Family benefits reported by both groups were also consistent with previous findings (King et al., 2011; Manor-Binyamini, 2016) and reflected concepts of family closeness, interpersonal support, and development of empathy, tolerance, and strength.

'Social benefits' was a theme which emerged from the data in the WS group. Families reported a combination of appreciation and personal benefits experienced because of their family member's prosocial nature and ability to make social connections. This is congruent with a study by Klein-Tasman and Mervis (2003) which reported that children with WS can

be distinguished from children with other developmental disabilities based on specific personality characteristics such as sociability, empathy, gregariousness, and extraversion. Importantly, the social benefits described by this group reflect increased social support, which is recognised as one of the most significant resources available to people who are facing difficulty and crisis because it helps them cope with stressful life conditions (Bigatti, Wanner, Lydon-Lam, Steiner & Miller, 2011). Therefore, the increased social support experienced by families of children with WS may help to explain the finding by Fidler, Hodapp and Dykens (2000) that positive personality characteristics associated with WS inhibit parenting stress.

The impacts felt, and concerns raised, by families living with children with a developmental disability will depend of the type of condition and severity, as well as the physical, emotional, and financial situation of the family and the resources that are available to support them (Reichman, Corman & Noonan, 2006; Wei & Yu, 2012). The WS group reported some negative impacts arising from raising a child with WS, while the DS group reported negative stereotype challenges. Both groups reported similar engagement, planning, and vulnerability concerns. Negative impacts reported by the WS group generally included working reduced hours and activities of daily living. This is consistent with literature reporting that caregiver burden affects decisions about work, education, training, having more children, and diverts attention from other important aspects of family functioning (Wie & Yu, 2010). While it is likely that the DS group experienced similar impacts, interestingly their responses instead focused on the stereotype challenges they experienced and the need to advocate for their family member with a disability. Indeed, stereotype concerns represented the most frequent theme to emerge from the DS group data.

The International Classification of Functioning, Disability, and Health (ICF) has reported that negative societal attitudes are one of the most disabling factors for people with

disabilities (World Health Organisation, 2001; Pace, Shin & Rasmussen, 2010). Most participants in the DS group described encountering stereotype biases, discriminatory behaviour, and not being listened to. This is consistent with current literature which states that although self-reported attitudes toward people with intellectual disabilities appear to be improving over time, people with disabilities continue to experience social exclusion, limited social relationships and lower rates of employment (Scior, 2011; Walker & Scior, 2013). Unfortunately, there is a dearth of literature evaluating contemporary attitudes, stigma, and stereotype biases toward individuals with DS or, more broadly, individuals with intellectual disabilities. It is curious to note that stereotypes did not emerge as a theme for the WS group particularly given that WS is no less 'visible' a disability than DS. One explanation for the difference between groups may be the 'pro-social' WS personality and associated social benefits reported by their families however, further investigation to understand why stereotypes concerns were reported by the DS group but not the WS group is warranted.

Values emerged as a theme related to family and personal benefits with the DS group describing equality, inclusion, patience, kindness and helping others as important. Values espoused by the WS group had a greater focus on the concept of acceptance. King, Baxter, Rosenbaum, Zwaigenbaum and Bates (2009) evaluated the values and belief systems of families raising a child with Autism Spectrum Disorders and similarly reported that families adopted perspectives of appreciation, acceptance, and optimism. King et al. suggest that a family's ability to ascribe positive meaning to life events promotes their child's resilience and the resilience of the family unit and this was reflected in the family closeness reported by both groups in the current study.

Relatedly, positivity, in terms of cognitive appraisal, presents a psychological coping resource and predicts subjective well-being (Frerickson & Load, 2005) and family adjustment (Trute, Benzenes, Worthington, Redden & Moore, 2010). This is because positive

perceptions serve an adaptive function in response to life challenges. Positivity and the ability to ascribe positive meaning to raising their child with a disability was evident in most participants in the current study. There was, however, variation in the degree of positivity or negativity expressed by participants. One factor which was associated with increased negativity was a lack of social support. Participants who expressed more negative appraisals of their situation also cited a lack of social support and feelings of isolation. This is consistent with the wider literature which describes social support as a significant resource to support families to cope with stressful life conditions (Bigatti, Wanner, Lydon-Lam, Steiner & Miller, 2011).

The impact of receiving a diagnosis of WS in their child

Parents in the WS group reported several factors they attributed to a more positive experience of receiving their child's diagnosis. Specifically, parents valued clinicians who were informed about WS; who provided timely communication; and who used supportive, positive language. Additionally, parents valued receiving printed information about WS and contact details for family support groups.

Parents also reported factors they attributed to a more negative experience of receiving their child's diagnosis. These included clinicians who are unprepared or uninformed about WS, or provide out-of-date information; providing clinical information without reassurance or a balance of positive information; and providing diagnoses-related information over the phone.

Delivering 'difficult news' is a challenging exercise for clinicians, but it is clear from the current study that there are specific ways in which clinicians can improve the experience for parents. This is a worthwhile exercise because the information parents receive and the way in which they are told affects their adaptation to the diagnosis and subsequent decision making (Sheets, Best, Brasington & Will, 2011). Moreover, receiving a balanced perspective

about the positive and negative aspects of raising a child with a disability supports parents to embrace the challenges ahead (Skotko, 2005; Skotko & Bedia, 2005).

When asked to reflect on their experience and report factors that would have been helpful or supportive at diagnosis, parents made suggestions which were in line with positive and negative reflections. Parents reported that they would have liked support and advice post-diagnosis; up-to-date information; an empathic, supportive, informed approach; referral to a counsellor for support; and an information package to take away and digest after the diagnosis. Interestingly, these suggestions echoed the suggestions made by mothers of children with DS in studies by Skotko (2005) and Skotko & Bedia (2005). They reported that mothers of children with DS suggested that clinicians talk more about the positive aspects of DS; use more sensitive wording; provide opportunities or referrals to speak with other families of children with DS; and provide up-to-date, printed information about DS. Importantly, these suggestions were drawn upon when designing current guidelines for clinicians providing a diagnosis of DS. The current study indicates that parents receiving a diagnosis of WS desire many of the same types of information and support as parents receiving a diagnosis of DS. As such, the guidelines designed to support clinicians to address the informational and support needs of parents of children with DS may also be appropriate to support clinicians providing diagnoses of WS. The use of these guidelines may lead to a more positive experience for parents and support them in adapting to difficult news.

Strengths and Limitations

A limitation of the study was the use of open-ended questions in a self-administered survey which removes the ability to ask follow-up questions (Dillman & Christian, 2005). In addition, the questions asked in the current study may not have captured the full breath of families' experiences. Importantly, though, self-administered surveys have been shown to enhance participants sense of anonymity and elicit more truthful, less socially desirable

responses (Dillman & Christian, 2005). As a result, the perspective and recollections expressed by families in the current study are likely to be representative of families with a child with WS or DS.

Future directions

There is a dearth of research investigating the experience and support needs of older persons with WS. This is an important area to investigate as many parents reported concerns about planning for their son or daughter's future, especially after parents pass. It is plausible that the WS phenotypic personality structure changes with age, with one participant reporting that her daughter with WS had become less social and developed more challenging behaviours as an adult. Interestingly, there are well-documented risks for depression and Alzheimer's in older adults with DS; which are characterised by changes in personality/behaviour and executive functioning (Ball, Holland, Treppner, Watson & Huppert, 2008; Dykens, 2007). Studies are needed to investigate if such changes in older adults with WS are likewise predictive for health and wellbeing.

Conclusion

In conclusion, the findings of the current study can be used to inform clinicians and families starting out on their journey about the positive dimensions of raising a child with WS or DS, in addition to the hardships (King, Zwaigenbaum, Baxter, & Rosenbaum, 2011). Indeed, understanding the perspectives, values, priorities, and concerns of families raising a child with a disability is a hallmark of expertise in service delivery (King, Baxter, Rosenbaum, Zwaigenbaum & Bates, 2009). The current study indicates that parents of children with WS seek similar kinds of information to parents of children with DS. Therefore, guidelines which exist to aid clinicians in providing information to families of children with DS may also be appropriate for use in families of children with WS.

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Appendix A

Survey questions:

What has having a family member with WS/DS meant to you personally?

What has having a family member with WS/DS meant to your family?

What things or issues is your family most concerned about?

What sorts of things does your family celebrate?

What is important to your family?

Have your family values, worldviews, or priorities changed over time? (Examples welcome)

What kinds of challenges has your family faced and how are they managed? (Examples welcome)

Has WS/DS enriched your family and or your community? (Examples welcome)

What do you appreciate about your family member wit WS/DS?

Is there any other perspective, opinion, story, or anecdote you would like to share?

Appendix B

Follow up questions for the WS group

How did you learn of your child's diagnosis of WS? (i.e. in what setting, by whom-paediatrician/nurse/GP, in what manner, in what type of language).

Was there any information that you did not receive, but in hindsight would have found useful in helping you find support and/or learn more about the diagnosis of WS?

Do you recall anything specific that was told to you by your child's physician or other healthcare provider at the time you received your child's diagnosis that you found particularly helpful, supportive, or caring?

Do you recall anything specific that was told to you by your child's physician or other healthcare provider at the time you received your child's diagnosis that you found particularly not helpful, inappropriate, or insensitive?