

HEALTH-RELATED FAMILY QUALITY OF LIFE WHEN A CHILD OR YOUNG PERSON HAS A DISABILITY

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Abstract: Parents of a child or young person with disability face not only the same challenges as parents of typically developing children and young people, but also the extra challenges of supporting the child or young person with disability in such a way as to maximise both their own quality of life (QOL) and family quality of life (FQOL) for all family members. Health-related quality of life (HRQOL) encompasses not only physical health but also mental and emotional health, equally important for FQOL. This article builds on information from previous publications, and illustrates relevant issues and the innovative methods parents, caregivers, and professionals have devised to enhance the HRQOL for children and young people with disability, and to improve FQOL. The author draws upon her personal lived experiences of having two daughters, the eldest an adult with disability, as well as being the medical consultant and manager of a newly created health unit tasked with supporting students with disability, who often have high health needs, in educational settings. The health conditions selected are those that have a major impact, not only on the young person with disability but also on family members. Vignettes, all deidentified true stories, will be included to illustrate the multiple issues faced by children and young people with disability, their families and extended families, and treating clinicians. These stories will hopefully resonate with families in particular.

Keywords: health, disability, quality of life, family quality of life, health-related quality of life

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Until the early 1970s, health research focused on the population health statistics of mortality and morbidity (Thacker et al., 2006), rather than considering individual quality of life (QOL) or family quality of life (FQOL). Miilunpalo, Vuori, Oja, Pasanen, and Urponen (1997) claimed self-rated health status to be a health measure, with self-reported health status predictive of the use of physician services, and of mortality in the working-age population. Although this can be equally applicable to children and young people with intellectual and developmental disability (IDD), in cases where the child or young person is unable to communicate, reporting relies on observant parents or caregivers. Although Cummins, Gullone, and Lau (2002) warned proxy interpretations by a parent or caregiver might not reflect what the person with IDD would have chosen to communicate if able, Sigelman, Budd, Spanhel, and Schoenrock (1981) claimed that the reliability of self-reporting by people with disability had not been adequately explored; such exploration could better inform efforts to measure self-assessed health-related quality of life (HRQOL) by people who have cognitive impairments.

Until 2001, there was an assumption that disability had to be associated with poor health, but the World Health Organization's International Classification of Functioning, Disability and Health (ICF; 2001) reflected the fact that a person can be disabled but healthy, and introduced the concept that personal participation is an important component of health. For example, a child may have diplegic cerebral palsy (CP), and be unable to walk independently, but may otherwise be healthy if provided with opportunities to participate. The Special Olympics and Paralympics provide many examples of people who have a disability but are able to participate with support.

Purpose of this Article

This article is a collation of information and experience that I have gained in a number of ways, including working in a children's hospital child development unit performing developmental assessments, and working in preschools and schools, particularly special preschools and schools, responding to health-related and disability-related questions from parents and school staff. I was also involved in negotiating health support plans when there was disagreement between parental expectations and what education staff were permitted to do; in other cases, I was able to provide information about referral and treatment options for complex disability and medical situations. Additionally, my background includes working with parents, caregivers, teachers, and clinicians in relation to children and young people at the Centre for Disability Health in South Australia¹, serving on disability-related committees, presenting nationally and internationally at disability conferences, and lecturing in Disability Studies at Flinders University, as well as completing graduate degrees in Disability Studies.

¹ <https://dhs.sa.gov.au/services/disability-services/centre-for-disability-health>

The intention of this article is to provide as much practical information as possible, including information useful to families trying to support their person with disability as best they can. Such information may give them understanding and realistic hope for the future, providing their child or young person with disability does not have a degenerative condition, in which case the trajectory might be different. As published papers and books do not always offer the up-to-date simple practical information families are searching for, a number of vignettes are included later in the article. These focus in particular on autism spectrum disorder (ASD) and the anxiety usually associated with it. The vignettes all represent true situations, and are written from the perspective of the families. They have been selected to give a better understanding of the impact of health conditions on FQOL when there is a person with disability. Clinicians who have not had more than brief contact with people with ASD tend not to fully appreciate the impact of having a child or young person with ASD on FQOL.

Quality of Life

For the past thirty years, increasing awareness of QOL has become an important focus in providing support and planning interventions for people with IDD (Brown & Faragher, 2014a). There are many definitions of QOL in the general population, but in the field of IDD it is commonly regarded as relating to well-being (social, emotional, and material) as well as health, intimacy, safety, productivity, and community (Brown & Faragher, 2014b). A child or young person with IDD is claimed to have adequate QOL when their basic needs are met and they are able to pursue and achieve objectives in major life settings. Of particular importance to people with IDD are FQOL (Zuna, Brown, & Brown, 2014) and the subject of this article, health-related family quality of life (HRFQOL).

Family Quality of Life

FQOL has become an increasingly important topic of study with regard to families of a person with IDD. Numerous FQOL studies have been carried out in some 25 countries around the world (Parmenter, 2014) using two main information-gathering tools, the Beach Center Family Quality of Life Scale (Beach Center on Disability, 2005), and the Family Quality of Life Survey-2006 (Brown et al., 2006). Most of these studies have examined FQOL from the perspective of the main caregiver (usually the mother), and their main findings have been compared through collaborative research roundtables (Isaacs et al., 2007). In the past several years, the culmination of QOL and FQOL research within the IDD field has been highlighted in two special journal issues (Brown, 2006; Kober & Wang, 2011, 2012). Several key findings inform the approach of using FQOL as a foundation for support-based interventions. Families without a child with a disability scored higher (i.e., better) on QOL domains than families of children with disabilities; however, when comparing children with ASD against children with Down syndrome (DS), families of children with ASD scored much lower than those of children with DS across a majority of the QOL domains. External factors (e.g., lack of community services and supports), and internal family factors (e.g., family characteristics) may also impact

FQOL. A child with depression seems to be more challenging to maintaining FQOL than does the occurrence of IDD alone. Researchers also highlighted characteristics such as problem solving, family sense of coherence, positive coping, and positive adaptation as helpful in managing family life and a child with IDD. Such positive aspects illustrate that families do find ways to positively manage day-to-day life and remain resilient. This finding also supports earlier research in which some families noted experiencing positive perceptions as a result of having a child with a disability.

An overview of FQOL studies makes it apparent that families around the world respond to FQOL measurement tools in much more similar ways than might be anticipated, considering the wide diversity in culture and availability of services as well as economic differences (Brown, Kyrkou, & Samuel, 2016). Although raising a family is never without issues and challenges, this is compounded by having children with severe or multiple disabilities. The development of deinstitutionalisation and community inclusion has meant that more parents have again had to take on the primary support role for their offspring with disabilities. The past 20 years have led to a tremendous growth in FQOL-related literature based on practice and research, to the emergence of various methods of family support not previously considered necessary, and to consequent changes in policy and practice, including the development of partnerships between parents and practitioners. These developments rely to a large degree on mutual support and cooperation amongst a wide range of authorities whose personnel work with people with disabilities, but the impact of the changes on parents and siblings should be the primary consideration. Brown, Kyrkou, and Samuel (2016) also reported that “FQOL includes many concepts and principles, is lifespan in orientation, and requires a seamless service relevant to the health and viability of the family as a whole” (p. 2065). At the same time, FQOL is an emerging field of practice requiring ongoing research.

Data from over 20 countries using the FQOL Survey-2006 (Brown et al., 2006) indicate that the vast majority of mothers who have a child with IDD are expected to take on more responsibility than they want, leaving less time for the father and siblings (Turnbull, Brown, & Turnbull, 2004). The nature of disability over the past century has changed significantly due to medical and allied health interventions, education, and, more recently, inclusion of people with disabilities into general society. Although this has brought many gains, most parents now have responsibility for the care of their children with IDD from birth onwards; they also know that their children are likely to live longer than would once have been the case, and will need educating for adult life. Improvements in their QOL, and therefore personal development, could mean that some children with IDD who survive to adulthood can manage without the total support from parents and health authorities which they would otherwise require. The nature of IDD implies the need to ensure that the FQOL is preserved, necessitating integrated and inclusive services involving health, social and community services, and education — a challenge requiring changes in policy development. The changing nature of disability, with increasing

severity in some cases along with an increasing lifespan, has implications for the survival and effective functioning of the family as a whole.

Health-Related Quality of Life and its Measurement

The literature contains many articles that include “HRQOL” in the title but do not offer a definition. Where the term “disability” is also included, it is in the context of a disabling physical condition, not IDD. Efficace and colleagues (2003) claimed there was broad agreement that HRQOL referred to the physical, psychological, and social functioning of patients, and to the impacts of disease and its treatment on their abilities and social functioning. According to the Centers for Disease Control and Prevention (2011), HRQOL can be divided into two levels. The first, the individual level, includes both “physical and mental health perceptions (e.g., energy level, mood); and their correlates, including health risks and conditions, functional status, social support, and socioeconomic status” (para. 4). The second level, the community level, encompasses the “resources, conditions, policies, and practices that influence a population’s health perceptions and functional status” (para. 4). The “gold standard” of generic HRQOL measures is the Medical Outcomes Short Form-36 (SF-36; Krahn et al., 2009), with scores on the eight domains of physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health, plus two summary scores for physical health and mental health. In spite of being considered the gold standard, the SF-36 is less applicable to people with IDD, because the physical domain includes questions regarding walking, climbing, kneeling, and lifting, without any distinction between long-term physical impairment and recent deterioration. Many people with IDD participating in the Special Olympics and Paralympics would probably score low on the SF-36, despite being generally healthy.

From Health-Related Quality of Life to Health-Related Family Quality of Life

When a family member has a severe, profound, or multiple disability, the impact on the family calls for considerable social community support, as well as effective health and education services. The associated stress may place parents in very difficult circumstances, sometimes resulting in a family living apart from other relatives, or a single mother not having extended family available to provide help. Policies have to be developed that take into account not only the needs of the child, but the needs of and resources required by other family members. For example, siblings need to have appropriate opportunities in their own lives in terms of family living, education, and social life. Although many countries have developed inclusive education, they have found that some individuals cannot be managed in regular schools. Consequently families, generally the mother, are asked to take their child or young person home to protect education staff from abuse, but that policy leaves the mother herself very vulnerable to being verbally and physically abused at home.

Consider the impact on the family of having a child or young person unable to weight-bear or walk. Unfortunately, in many such families, a single parent, generally the mother, has to

exist on social services because of limited work options, and cannot afford extra help or equipment. To protect staff from injury, services require all lifting of students or clients to be done using hoists, or if not available, with two-person lifts. In contrast, when the student or client arrives home, it is often the single mother who has to manually lift her son or daughter out of the bus or taxi into a wheelchair. Imagine attempting a shopping trip with the child under such circumstances, and contrast that with the ease with which most of us get out of the car, take our typically developing child by the hand, quickly make our purchase, and walk back to the car.

Parent support groups are often used to meet the emotional and informational needs of families. Singer et al. (1999) conducted a multisite evaluation of parent-to-parent support groups, and found that families who are supported by other families in parent-to-parent mentorships achieved greater gains in coping mechanisms, attitudes, and meeting their primary needs than did families lacking parent mentors. Parents of children with ASD benefitted by sharing and learning from one another, and supporting and accepting one another, as well as learning instructional strategies, communication methods, and behavioural techniques.

Parent support groups are also a positive source of support for parents of children and young people more recently diagnosed with disability, in that some members will have considerable family life experience and know many informal ways to improve their FQOL. They also may have valuable recommendations for improving policy and practice. Many families cope well, possibly due to a number of relevant variables such as family values and attitudes, confidence, family coherence, and problem-solving abilities — properties that seem to enable parents and other family members to deal with stress and present what can be termed individual and family resilience.

A study by Brown, Kyrkou, and Samuel (2016) reported that when there is a child with IDD, “fathers as a rule have very strong feelings and frequently seek ways to support the rest of the family” (p. 2074). They did acknowledge, however, that most informants were mothers; from personal observation, this is not much different to families without a person with IDD, as there is usually a preponderance of mothers at parent-teacher interviews and other daytime meetings or functions. When taking my daughter back to her accommodation, I was initially surprised when her house manager stated that my husband and I were “an odd couple”, by which she meant we were still together as a family. In my work role, my experience of fathers of children and young people with IDD, mostly ASD, has been different. I estimate that approximately 50% of those fathers lived with and supported their family, the other 50% of mothers reported that their husbands had left the marriage when their child with ASD was a toddler. The mothers’ descriptions of their husbands in many instances suggested that they also had ASD. The researchers also recognised that family attention may be diverted from other family members because of the needs of the individual with disability. Many families have to cope with a family member temporarily under stress or in ill health, but when it is prolonged and associated with a child with multiple disabilities and behavioural challenges, such as a child with ASD, it becomes

a major issue for FQOL, sometimes resulting in some family members moving out of the family home.

For mothers in particular, chronic tiredness is a major issue because of constantly having to advocate for services and take the child or young person to appointments, as well as their child or young person not sleeping well through the night. A mother requires sufficient time for other members of the family, and to meet and sustain her personal major interests and needs. Without this, her physical and mental health and that of other family members is likely to be compromised. The mental health needs of family members may need to be addressed to limit impacts on family members that would complicate intervention and support.

A clinical description does little if anything to convey the impact on the family of a child or young person with disability and related health issues, and clinicians who have not had more than brief contact with children and young people with ASD tend not to fully appreciate the impact on HRFQOL. This problem becomes more urgent in light of the reports of an apparent increasing incidence of ASD, but evidence for the increase is controversial, with Gillberg (1999), and Wing and Potter (2002) both suggesting the apparent increase is due to changing diagnostic criteria, and increasing awareness of ASD. Gillberg (1999) reviewed studies from 1966 to 1997, finding rates of 0.5 per 1,000 in those born before 1970, but higher rates of 1 per 1,000 in those born after that. In 2006, Gillberg, Cederlund, Lamberg and Zeijlon assessed all children in Gothenburg Sweden, born between 1977 and 1994, finding a rate of 2.05 per 1,000 for the whole cohort, but in those children 7 to 12 years old, the prevalence was 1.23 per 1,000. Wing and Potter (2002) pointed out that for decades after Kanner published his original paper in 1943, autism was considered to be rare, with a prevalence of 2 to 4 per 10,000. However, studies in the late 1990s and in the current century are indicating annual increases, of up to 6 per 1,000 for autism, and even more for autism spectrum disorder, which includes Asperger syndrome. I hope the vignettes in the following section prove useful in understanding the impact on HRFQOL of having a family member with disability, especially ASD.

The Early Years

During pregnancy, most parents are anticipating an uneventful delivery of a healthy baby. Particularly with the firstborn, even if typically developing, parents worry about minor changes in breathing, feeding, sleeping, movement, or bowels. Some parents become aware before or soon after birth that their baby has a disability, others bond before being made aware their baby has a disability. Unfortunately, I have met many parents who realised their child had something wrong, but could not get clinicians to recognise this until months or even years later. Consequently their child missed out on early intervention services, and the parents were not able to access appropriate information and support, including financial support. In the early years in particular, talking to other parents facing the same issues is very important psychologically, offering the added benefit of information exchange. Although there are numerous forms of disability, I have featured children and young people with ASD, and the anxiety usually

associated with it, in many of the vignettes below because of their unpredictable anxiety responses, and extreme meltdowns.

Parents of children with IDD, and particularly ASD, have admitted to running themselves ragged trying to get as much therapy and education as possible into their young child, as clinicians have told them that what their child has not learnt by five years of age, their child would never learn. I have had the opportunity to observe students in my daughter's special school continuing to develop through their school years, and onto post-school options, whereas paediatric clinicians who are not also parents of people with disability generally do not have the same opportunity. Parents and caregivers have sometimes reported that information in books, even those relating to people with IDD, does not reflect what they are observing. Because treating clinicians who do not have long term exposure to people with IDD have to be guided by the literature, when parents give history not consistent with the literature, there is a disappointing tendency for their observations to be discounted.

A young child with IDD initially attended a day centre for children with CP, but once she began walking at 22 months, the service no longer suited her. To be enrolled in a special preschool, she had to be registered with a specific government disability agency, where she was offered in-home therapy. The therapist soon realised she was very adept at avoidance. When she did not want to cooperate, which was often, she would sing, and everyone would be so taken with her melodic singing voice that they overlooked the fact that it was avoidance behaviour. Alerted to it, the family was no longer distracted by her avoidant singing.

Intellectual and Developmental Disability versus Autism Spectrum Disorder

I became aware from my formal development assessment training that, except for those children and young people with degenerative conditions, the child or young person with IDD progresses through the same developmental pathway as typically developing children and young people, albeit more slowly, and they continue this mostly predictable progress through adulthood.

Over the years I have become very aware of many children and young people who were known to have IDD, and had been assessed for suspected ASD when young, but whose parents had been told their child did not have ASD. Some clinicians dispute the need for a second label, but from my personal experience, for the first 14 years of my daughter's life with a diagnosis of IDD, clinicians and our family struggled with her resistance to complying, and her lack of imitation skills. Our family's worst experience came when our daughter was 4 years old, and a respected psychologist demonstrated how to control her resistance, by placing her face down on the carpet, and pinning her down by kneeling on either side of her body. As soon as she was released, she consistently went back to what she was doing. When she was diagnosed with ASD at 14, the management difficulties we had experienced largely disappeared because we understood the underlying mechanisms, and approached the issues differently. An example of

our changed approach was to wait longer for her to process a request, such as getting out of the car, and not to repeat the request using different words, as she would then have to process the new wording.

I saw a number of teenagers with IDD referred to the Centre for Disability Health for a psychiatric assessment of challenging behaviour. Most had been assessed for ASD when young, but their parents had been told their child did not have ASD. Taking a history often brought to light a number of features of ASD, and a diagnosis of ASD would then be confirmed by accredited clinicians. Being able to explain to parents that the behavioural difficulties were mostly due to ASD, and helping them work out strategies to improve FQOL for all, or referring the teenager to a psychologist, meant only a few teenagers still required psychiatric services.

The mother of a 15-year-old female with IDD and severe epilepsy who was returning to school after many years of home schooling made a simple comment: “I don’t know how I am going to convince her not to have her hair washed on Tuesday mornings.” I had known the student and her mother for many years, and knew the mother did not make exaggerated claims. This passing comment led me to ask more questions about possible ASD, leading to a diagnosis. The confirmation of ASD meant her needs at school were better understood.

The father of a 5-year-old boy with IDD rang me in panic one afternoon, saying his son with IDD had tried to kill his younger brother, and the parents were afraid to keep the 5-year-old at home any more. It turned out that the boy always watched a Disney movie at midday on Sunday, and thoroughly enjoyed it. He turned on the television, and his program came on, but when he only saw black-and-white instead of colour, he went into blind panic mode, and ran away from the television. He was oblivious to his younger brother being in his way. The boy was awaiting an assessment for ASD, so the father was not worried when I mentioned ASD as the possible cause of the episode. The same boy’s mother recounted an episode where she could not understand what had gone wrong. Her son had been attending speech pathology without incident for many months, but she felt very embarrassed when he screamed continuously for two successive sessions. Talking it through, she realised that the speech pathologist had usually worn a black skirt, but on one of the two days she had worn a red skirt, and on the second day she had changed her hairstyle: she had not realised that children with ASD do not cope well with even minor change.

I was asked to visit a 3-year-old girl because of the child and family health nurse’s concerns that she might have ASD. The backyard had a very high fence, and there were graders working close by. Her siblings ran to the fence and climbed up, but the girl ran to the swing, signalling for her mother to push her up high. As soon as she was as high as the top of the fence, she turned to look over the fence. She had an ASD assessment, but was not given a diagnosis of ASD. At the age of six years, school staff re-referred her for an ASD assessment, and she was diagnosed with Asperger syndrome.

I had just completed a developmental assessment on a 3-year-old boy. As he was leaving he grabbed a toy car from the table, but his mother made him put it back. He picked up a ball and walked out into the waiting area, but then, as I anticipated, he came back through the door of the consulting room, approached the table, threw the ball to the other end of the room, grabbed the car, and ran off. When his mother took the car from him, he had a meltdown; he was subsequently confirmed to have ASD.

A 9-year-old aboriginal boy with IDD attending a special school had repeatedly attempted to run away by jumping a high fence bordering a busy road. School staff attributed this behaviour to the fact that he was aboriginal, as stories of aboriginal people absconding had often appeared in the media. I did not suspect that he had ASD until he had to have blood taken. It was difficult to get blood from him, but he sat silently until it was finished, then went out into the passage, going onto his knees and just rocking silently. A child with IDD screams under those circumstances, unlike this boy, and a subsequent ASD checklist showed many features of ASD. His running away took on a different meaning when staff realised it was due to ASD, anxiety, and sensory overload. With his difficulties being better understood, and with appropriate therapy, he matured into a capable teenager, participating successfully in the Special Olympics.

Communication, QOL, and FQOL

Facilitating a person with IDD to communicate is the underlying basis for enhancing QOL, improving the person's self-image, self-esteem, and social-emotional development. Improved capacity for communication may lead to the person being able to indicate symptoms of health problems earlier, potentially reducing their long-term impact. Many people with ASD seem to expect others to know what is wanted without having to indicate. If the child or young person with ASD does indicate by pointing, it is not the customary clear gesture using the index finger, but rather a hand vaguely indicating the direction of what is wanted. In my experience it is often more useful to observe the eye movements of the person with ASD, realising that the child or young person may only focus briefly on the desired object and not look at it again. Not getting needs met is one cause of a meltdown in a person with ASD; another is being told "No" to a request (sometimes terms such as "not jumping" may get less reaction). Unfortunately meltdowns can last for hours, and are often noisy, impacting adversely on FQOL.

Some parents and clinicians are unaware of the many, mostly nonverbal, behaviours that precede spoken language, but also are of the opinion that a child with IDD taught to sign will never learn to speak. On the contrary, the use of signing helps the child understand the number of syllables in the words being learnt, and helps the development of words. Parents have spoken of taking their child with IDD and ASD to a clinician or therapist, pleased at the nonverbal progress their child has made, including using consistent vowel sounds in a word, such as "ee" for "cheese". They feel deflated and belittled when it becomes obvious the clinician or therapist does not recognise the progress the child has made because the child is not using clear words appropriately. Many children and young people with ASD do not understand that using

deliberate communication, even if nonverbal, would convey their needs more effectively and lead to less frustration and fewer meltdowns.

Paediatricians and paediatric registrars² who have completed formal developmental assessment training are more likely to recognise the significance of preverbal skills. A paediatric registrar who had just completed developmental assessment training in our unit relayed his experience in a gastroenterology unit. During the ward round he realised the 3-year-old patient was not speaking, but that fact had been overlooked with the focus on the child's gastrointestinal tract. In the longer term, the lack of communication would possibly have been more of a problem for both the child and family than the gastrointestinal disorder.

Hospital, Medical, and Therapy Services

Hospitals are an important service for children and young people with disability who require medical or therapeutic supports, but there can be lack of continuity of clinicians when the child or young person is not being managed by a dedicated unit for children and young people with disability. Although some admissions are planned in advance, many are the result of acute admissions through the emergency department, which means the patient is admitted to whichever ward has a vacant bed. Once my daughter was admitted in the early evening, after a prolonged seizure, and was still febrile, and thus at risk of further seizures. As she was wheeled into the geriatric ward, the charge nurse came out to say she couldn't possibly go into the ward, as she would wake up the elderly patients; she had to go into the side room. Needless to say, I stayed the night, dozing in an uncomfortable lounge chair. The following day a nurse was allocated to "special" her, which meant keeping an eye on her all the time.

That afternoon, as I walked out of the lift I happened to see a patient in a white gown running fast down the long corridor, followed at a distance by a nurse. My daughter was very fast at seizing an opportunity to escape, often catching the person looking after her by surprise. She would not stay in bed once awake, even at home, and she was too strong to try walking alongside holding her hand. While she still fitted into her stroller, I walked her along the corridors in that, but after that I had to wait for a vacant wheelchair. One day an elderly patient was getting into the ward wheelchair, which my daughter thought should be for her; she was going to try to wrest it from the woman until I intervened. Ten years ago my daughter developed marked muscle weakness, so had her own wheelchair to take to hospital.

Waiting for appointments was always challenging with my daughter. When she was young the neurology department had a large rocking horse that she loved, but she didn't understand why she had to share it with other children also waiting. When she had an appointment with her ear, nose, and throat specialist she was too noisy to be in the waiting area when hearing tests were being done, so we walked up and down stairs and along the outside

² In the Australian medical system, a registrar is a doctor who has completed a residency and has joined a specialist training program.

balconies until we were called for her appointment. Ringing ahead of such appointments to check whether one should arrive later reduces stress on everyone.

Medication

People with ASD tend to be very sensitive to medication dosages, but doctors who have not had experience with people with ASD assume their ability to tolerate medication is no different from that of people in the general population, so they prescribe the recommended doses, sometimes resulting in serious side effects. Increasing and decreasing medication dosages also needs to be done more slowly than for patients in the general population. In the early years, my daughter had frequent major seizures (status seizures) for which she was taken to Emergency by ambulance, and often admitted. She was on sodium valproate (Epilim), and carbamazepine (Tegretol), with both doses being gradually increased in hospital. She was very agile, and usually had no difficulty getting herself up from the floor, but on two occasions about two hours after her night doses of medication, she could not get off the floor, and her pupils were very dilated. Another night she was all right when she went to bed, but an hour or so later we heard high-pitched screaming that reminded me of patients with cerebral irritability. The screaming increased when we touched her, or the ambulance officers tried to check her pupils. She was then heavily sedated and was so non-responsive overnight that we worried about what she might be like when she woke up. Fortunately she was all right, but her neurologist noted that with the two earlier episodes her carbamazepine level was 41 (recommended range 20–40), and with the cerebral irritability her level was 43. Medically we would not be concerned about those levels when they were only minimally above the recommended range.

The neurologist decided to gradually withdraw her carbamazepine but she had so much trouble with withdrawal seizures that he decided to keep her on a lower dose. Each time she was taken to Emergency with a seizure, her blood levels would be checked, and her carbamazepine levels were low, so the dose was appropriately increased. Three weeks later (the time interval until the increased dose would be effective), school staff contacted me to see if her dose could be reduced again, as she was so hyperactive. She was also hyperactive at home, and went from being a good sleeper to having difficulty sleeping. This is just one example of the many medication interactions and reactions my daughter has had.

Medical Conditions

There is a tendency for any health or behavioural issues to be dismissed by clinicians as just being part of the child or young person's disability, and therefore not requiring specific treatment. Some conditions are more common in children and young people with certain disabilities, but they still require specific management, while other conditions occur with the same frequency as in the general population. As early as 1995, Beange, McElduff, and Baker published a population study of the medical disorders of adults with mental retardation, showing,

for example, that up to 50% had undiagnosed and untreated vision or hearing defects. Dr. Helen Beange was one of the first doctors to integrate clinical practice with research in the IDD field.

Epilepsy

In families without a child or young person with disability, events can generally be expected to occur as planned, without the need for contingency plans. Children can confidently look forward to their birthday parties, knowing they will happen. In families with a child with disability who may require emergency management, on the other hand, parents often attempt to avoid building up expectations when they cannot guarantee that an event such as a party will happen. When my second daughter was in preschool, she was asked to be a model for development assessment training. Although she performed very well, the assessor expressed surprise that she did not know when her birthday was, but understood why when I explained we avoided building up too much anticipation because her birthday was in the summer, when our daughter with disability was more prone to having seizures requiring urgent admission to hospital.

Families with a child or young person with IDD and epilepsy soon learn to work around whatever happens, often having to change plans at the last minute. For example, one January, family from another state were arriving to celebrate my elder daughter's birthday that night. As it happened, a heat wave occurred and the air conditioning in her accommodation broke down. Having fever-aggravated seizures, she had a major seizure and was transported to hospital by ambulance. Emergency department staff knew her quite well from previous attendances, and knew that her seizures persisted if she was febrile. She was given rectal paracetamol (acetaminophen) only, even though I pointed out that she was still very stiff and probably going to have a further seizure. A short time later, she did indeed have another seizure, with the consultant unsuccessfully trying to insert an intravenous line into my daughter's jerking body. My suggestion of giving intramuscular midazolam was gratefully accepted by the consultant, and two hours later we all enjoyed celebrating her birthday with family. Things many families take for granted in terms of planning, such as holidays, cannot be taken for granted when there is a person with IDD and epilepsy in the family.

The unpredictability of seizures in children and young people causes difficulties for families, including not being able to travel by plane, or travel too far from medical support in case the child or young person should have a major seizure. Consider the situation of a single mother of four young girls, separated because of her husband's violence and abuse. Her youngest daughter has severe epilepsy requiring transfer to hospital, frequently at night. The three girls are too young to be left at home alone, and the ambulance is unable to wait for the maternal grandmother to get there, so the sisters have to go to hospital with their mother, following the ambulance, and taking their sister's wheelchair, which the ambulance cannot. Having been up most of the night, the sisters are too tired to go to school the next day, but their sister is usually kept in hospital several days, so their grandmother has to pick them up and look after them.

The father of a young boy with CP and epilepsy was sitting in a shopping centre, with his son in his wheelchair, waiting for a taxi to take them home. They could not afford a car, as neither parent was able to work when they had to be on call to go to their son's school if he had a major seizure, and there were two younger children at home with no options for them to be looked after at short notice. When the boy had a major seizure, his father was able to bring it under control rapidly by administering intranasal midazolam; then he sat nursing his son until he recovered. The father said he got some odd stares from people but that didn't bother him — he was just relieved his son didn't need to go to hospital by ambulance. If his son had needed an ambulance, it would not have been able to take his son's wheelchair. The father would have had to take the wheelchair to the hospital in a taxi at full fare because his son wasn't travelling.

Tube Feeding

The advent of tube feeding for people with swallowing difficulties has revolutionised their medical care, with improved QOL and longevity. During the middle to late 1980s (Minard, 2006), the practice arose of placing feeding tubes surgically for better results. Since then there has been little change in the protocols, although placement has been enhanced by endoscopic, radiologic, and laparoscopic modifications.

Over the past two or three decades, medical progress has been such that increasingly premature babies have survived, but many had CP and breathing or swallowing difficulties. Many of these babies had weak cough reflexes, so that food and fluid went into the lungs (aspiration) instead of down the oesophagus to the stomach. This often caused pneumonia. Every episode of aspiration, as well as every episode of pneumonia, damaged more lung tissue, progressively reducing the ability of the lungs to provide oxygen to the body. If aspiration, or the potential for aspiration, is recognised in the young baby, preventative measures need to be put in place immediately to avoid recurrent episodes of pneumonia. Current options include not only careful positioning in relation to feeding, and feeding of thickened fluids, but also feeding through either a nasogastric tube or percutaneous endoscopic gastrostomy (PEG).

In the education setting, the mother of an 8-year-old boy who was wheelchair-bound due to disability approached our program for help because he had put on so much weight that he was virtually wedged into his wheelchair. This occurred in the early days of our program supporting students with disability, but after speaking with his mother, looking at his feeding regime, and speaking with his dietitian, it became obvious that at that stage all the dietary guidelines were written for able-bodied, typically developing children who were physically mobile. This situation gradually improved once the dietitian's plan included adjustment for the activity levels of the child or young person.

As part of my work at a health unit, I was tasked with supporting students with disability, who often had high health needs, in educational settings. The mother of a 4-year-old girl rang me the week before her daughter was due to start preschool, an event that she was excitedly looking

forward to. The girl would require tube feeds during preschool, and she would be attending an early intervention service one day per week. At the end of the previous education year we had carefully planned for the preschool and early intervention days to not clash. The mother was upset because the manager of the early intervention service had just rung her to say the therapists had met and decided to change their early intervention day. When the mother pointed out that the early intervention day was the day her daughter was enrolled for preschool, and that a staff member had been allocated for the feeds, the manager told the mother the therapists would not be changing their day, so she had to decide which service she wanted. No mother of a child with disability should have to choose between two services that are equally important for her child. The early intervention service was definitely not client-focused, which was especially disappointing given that it was a long-established and previously well-regarded disability service. Fortunately, however, our service managed to change the day of support for the young girl.

Upper and Lower Respiratory Tract

A nonverbal young adult male with IDD had appeared to have headaches since his mother had died two years previously. He had early morning waking and outbursts of violence, punching his ill father and caregivers and damaging property. He was moved from living in his father's home in a country town to a large city a long way from his home, and was started on antipsychotic medication; however, his condition continued to decline. A brain scan showed sinusitis (infection in the air passages around the nasal areas) and antibiotics were administered. He was also prescribed an antidepressant. The headaches and aggression stopped within 48 hours, too soon for the antidepressant to have started to take effect; unfortunately, he had side effects from the antidepressant and required hospital admission. Failure to diagnose the sinusitis, not related to his IDD, denied him HRFQOL and moved him away from all his familiar supports.

Whether or not a person has a disability, poor health can markedly impair HRFQOL. Consider breathing difficulties, for example. Breathlessness limits a person's ability to talk comfortably while walking, exercising, managing physical household duties, sleeping, or holding down a job. As the breathing difficulties increase, the person may require continuous oxygen through a mask or nasal prongs, carrying or pulling small oxygen cylinders everywhere. Storage of the highly inflammable oxygen cylinders has to be away from naked flames, and the fire brigade needs to be alerted because of the risk of explosion. The ability to travel is limited by the need to stay close to replacement oxygen supplies.

Gastro-Oesophageal Reflux

Most children and young people referred to the Centre for Disability Health were referred for challenging behaviours, with a request for a psychiatric assessment. In our protocol, exclusion of medical conditions was the first stage of assessment. An 8-year-old boy with ASD

was brought in by his mother because his school staff were all wearing leather arm guards to protect themselves from his pinching and biting. His paediatrician increased his risperidone, but his behaviours continued to deteriorate. On specific questioning, his mother stated that he had reverted to drooling a lot, burped a lot, had sudden rushes of fluid or food regurgitation, often gave a sudden unexpected cough, and woke up with stomach pain during the night. After one month on liquid antacid, his symptoms resolved. His mother gained an understanding of the effects reflux can have, and she was able to start him back on the antacid if his symptoms recurred.

Another five nonverbal young people with IDD also presented with challenging behaviour, and were diagnosed with reflux. One 18-year-old with ASD started screaming about an hour after meals, but because he would still only take smooth foods such as yoghurt, and refused to eat the yoghurt if he could smell or taste anything added, I advised his elderly grandmother to check with the pharmacist to select the most bland liquid antacid. One teenage boy with CP had stopped eating, cried excessively at night, and was self-harming; another, also with CP, was swallowing frequently and arching his back while sitting in his wheelchair. One teenager with IDD started hitting co-tenants, self-injuring, and damaging furniture, while another was awake all night, crying more, and not eating, but drinking a lot of iced milk coffee (milk is an antacid, but being thinner, it doesn't stay in the stomach long enough to adequately neutralise the stomach acid.) The symptoms described above were all due to the pain of stomach acid irritating the oesophagus, and all responded to antacid medications.

Diabetes Mellitus Type 1

A nonverbal boy with ASD and IDD was diagnosed with diabetes when he was 2 years of age, but his diabetes had been extremely difficult to stabilise. When a person has Type I diabetes, early detection of symptoms means earlier and easier control of the disease, but that relies on the person being able to report symptoms, which this boy may never be able to do. Consequently at all times he needed someone with him, either a parent or a trained person able to detect slight changes and respond appropriately. His grandparents were able to look after his siblings, but they were too frightened to look after him without support. Without funding to provide a trained caregiver to monitor and manage his diabetes, he was not able to attend after-school care or vacation care with his siblings.

Because he unpredictably required emergency management, and sometimes hospitalisation, family holidays were restricted to locations close to major paediatric hospitals, and plane travel was not considered safe for him. Although his siblings were very understanding, their mother felt guilty that they were missing out on opportunities afforded to children growing up without a person with disability. She also felt guilty that she was not able to attend their school functions, and that they did not want to invite their friends over.

Bladder and Bowel Issues

Toilet training is accomplished very easily in some children with disability, but for many it is a slow and frustrating process. Although typically developing children commonly become toilet trained between the ages of 2 and 3 years, in children with disability toilet training occurs at a developmental age, not the chronological age. Sitting the child on a potty or on the toilet after a meal is worth doing to get them used to being on the toilet, but one should not expect any urine or a bowel action to be passed. The child should not sit for longer than 5 to 10 minutes, and should be taken off immediately if frightened or resisting staying on the toilet. Until the child is showing some signs of being aware of urine or a bowel action coming, forcing the issue is likely to result in long-term difficulties. One thing we cannot do is make another person void: turning on a tap may work on adults, but generally not on children.

Summer is generally the best time to start toilet training, when the child can be outside with just ordinary underwear on, and will hopefully associate the feeling of being ready to void with the feeling of urine running down his or her legs. Many parents have later regretted allowing their child with disability, especially one with ASD, to urinate or defecate out in the garden or other open areas, as the child did not understand the difference between the garden at home, and the schoolyard — unacceptable behaviour at school, but difficult to change. I have seen a number of older children and teenagers who are still wearing disposable pull-ups at night, and may be dry though the day, but will not have a bowel action until their pull-up is put on before bed, a pattern that is also extremely difficult to break once established.

Many children with disability have constipation, partly due to restricted diets, especially in children with ASD. Some do not like part of themselves going down the toilet, or the sound of the toilet being flushed. After a meal the gastrocolic reflex pushes food remnants into the bowel, but when the bowel is already full, severe cramping pains result. Constipation can also cause a tear in the anus as the bowel action is passing through, with painful spasms occurring every time a bowel action goes through. This can last for weeks to months, causing the person to hold on to the bowel action, exacerbating the constipation. Extremely severe constipation can put pressure on the bladder, with back pressure in the ureters going up to the kidneys, distending them, and ultimately causing kidney failure. I am aware of two children with disability who died from kidney failure secondary to severe constipation, so constipation cannot be ignored as not being important to treat.

Pain

Parents have told me of their frustration and despair when clinicians, especially medical and dental professionals, either say that people with disability must not be experiencing pain because they do not report having pain; or they say that people with disability have a high pain threshold and do not feel pain, and therefore do not require pain relief. A father contacted me late one afternoon to say that his son who had CP, IDD, and epilepsy, had just come back from recovery after having orthopaedic surgery in a major children's hospital. He was pale and

jerking, and his parents, sure he was experiencing pain, were very worried about him having a major seizure, with the risk of adversely impacting his surgery. They asked the senior surgical registrar if their son could be given some pain medication, but their request was refused. Unfortunately their son did have a major seizure, and was then medicated. The following morning, the senior surgical consultant, on hearing what had happened, made the surgical registrar apologise to the parents. Points to ponder: Did the registrar believe the myth that children with disability do not feel pain? If the boy's sutures had pulled apart, who would have been blamed? Although some people with disability are able to state that they have pain in some or all situations, many are unable to, but the observant parent or service provider will be able to notice the nonverbal indicators of pain, providing they know what to look for.

Offered the opportunity to complete a Master of Disability Studies at Flinders University, South Australia, and having been unable to adequately answer questions asked by teachers and parents concerning premenstrual syndrome (PMS) in females with disability, I accepted the opportunity to further research the condition. By the end of the study, I realised that what was being labelled PMS appeared in some instances actually to be pain, but I was not able to offer readers a reliable means of distinguishing between the two conditions in nonverbal females with disability. I decided to undertake a PhD (Kyrkou, 2009) to further research aspects of the menstrual cycle and pain in females with disability. The survey included females with DS, ASD, CP, and IDD, ranging in age from 10 to 44 years, with a median age of 18 years. Although 470 surveys were posted or emailed out, the response rate was only 23.8%, which is not surprising as it is such a confronting topic for many mothers of young females with disability; additionally, my survey would have been just one of the many sent to parents of people with disability. On the positive side, the 95 mothers and 7 daughters who responded provided great detail, particularly in relation to puberty and pain — information not previously published. For 66.6% of females breast development was the first sign of puberty, while 31.6% had pubic or axillary hair first (compared with only 10% among typically developing females). The other 5.3% had their first period before exhibiting any breast or hair development. Surprisingly, 56.4% had monthly cyclical symptoms before their first period (menarche) — in one case over a span of 30 months — that lessened as the menarche approached. Mood changes included irritability, being uncooperative or aggressive, and exhibiting challenging behaviour. Physical changes included abdominal cramps, vaginal discharge, increased seizures, vomiting, incontinence (bladder, bowel, or both), weight gain, back pain, and headache. Forty females (52%) had their menarche within 12 months of the first sign of puberty, yet the literature states that menarche typically occurs 2 years after the onset of puberty. Imagine the distress of the mother of a female with DS aged 10 years when the girl had her first period just 3 months after her endocrinologist had said she hadn't reached puberty.

To elicit behaviours suggesting the female with disability was in pain, I used the Non-Communicating Children's Pain Checklist – Revised by Breau, McGrath, Camfield, Rosmus and Finlay (2000) as a basis for the questions (Kyrkou, 2009). In the following paragraphs, I report

findings from my survey, with quotations grouped according to the nature of the disability, as there were some unexpected differences between the four groups in terms of pain presentation.

Females with Down syndrome: Hennequin, Morin, and Feine (2000) claimed that rather than individuals with DS being insensitive to pain, they express pain or discomfort more slowly and less precisely than people in the general population. They cited Lind, Vuorenkoski, Rosberg, Paratanen and Wasz-Hockert who studied the vocal responses of infants with DS and found they needed more stimulation to cause crying, and took longer to react. They also noted that this lack of cry response increases with age: children with DS over 1 year of age do not show the visual responses of grimacing, limb movements, or breaks in respiration seen in typically developing infants.

The most common nonverbal indicators of pain observed in my study were: not moving, being quiet or less active, seeking physical comfort and closeness, and crying moderately loudly. When hurt or unwell, 78.6% were able to say they had pain, but more females with DS were able to point to or touch the painful area than females in the other three groups. Survey responses included:

Yells, kicks, screams with severe pain (when she broke her arm).

Surprisingly to me, as she is a very articulate person, she was unable to say her arm was hurting. I now know that she is unable to tell me (or I need to teach her to understand pain signals) when she is in pain.

Females with autism spectrum disorder: Nader, Oberlander, Chambers, and Craig (2004) expressed concern that professional and scientific literature, on which information given to parents is based, states that people with autism are insensitive to pain. This has the potential to result in underestimation of pain, with consequent lack of appropriate assessment and treatment. In my study, the most common observations when the female with ASD was considered to be in pain were: not moving, less active, or quiet; and non-cooperative, cranky, irritable, or unhappy. Some females with ASD when in pain gave a small laugh, easy to miss and with no further sign. One respondent noted, “When in pain has facial pallor, is restless, and has excessive ‘jabber talk’.”

Females with cerebral palsy: Hadden and von Baeyer (2005) claimed people with CP are at greater risk than others for undertreatment of pain because of their behavioural idiosyncrasies such as moaning, changes in facial expression, sleeping patterns, and patterns of play that are inconsistent and difficult to interpret because of physical problems. Additionally, they observed that society appeared to value the comfort of children with CP less than that of other children. In my study, the main observations for females with CP in pain were: being non-cooperative, cranky, irritable, or unhappy; moaning, whining, or whimpering; and making a special sound, cry, or laugh.

Females with intellectual disability: The main observations reflecting pain were: not moving, less active, quiet; seeking comfort or physical closeness; and crying moderately loudly. Survey responses included:

Has an abnormally high pain threshold. She recently had to have an appendectomy after she had been mildly unwell, with some fever and “sore tummy”. Her appendix was gangrenous and ruptured, and she spent almost 3 weeks in hospital as she developed abscesses, yet [she is] usually able to state she has pain.

If injured, occasionally laughs if it is mild pain, becomes agitated and laughs or sings with moderate pain, and screams and whinges with severe pain.

Something that should be extremely painful, i.e., shut hand in door, burst eardrum, no reaction. Something small, i.e., bump into something, cries with tears, yells.

Respite and Social Occasions

Parents of typically developing children are more likely to get breaks away from their children, with child care, preschool, and school as formal activities, and they are also more likely to get informal opportunities with grandparents, friends, or neighbours, as well as birthday parties and play dates. Parents do not generally have to worry about the child not being well looked after. By contrast, the parents of children with IDD, and particularly ASD, get few of those informal opportunities. One mother reported that her parents said they were willing to look after the typically developing grandchildren, but not the child with autism, so she got no break from her caregiving role. Even though needing that break, parents often worry about the child being all right, particularly if there are health needs, or challenging behaviours. In one family I worked with, the parents were in desperate need of a break from their young person, but unfortunately, on her first overnight respite, their daughter sustained a broken toe. Subsequently her parents would not let her out of their sight. My concern in this situation is for the major impact on the daughter, an only child, when one or both parents die. When I discussed this with the parents, they just shrugged their shoulders hopelessly and said “God will provide.”

Before we knew our daughter had ASD, we went to family gatherings in the evening. One night she became very noisy and distressed, so we went home early. When we got home she sat down quietly, making us wonder if she was being manipulative. Once she was diagnosed with ASD, we understood the noisy echoing room was bothering her. My sister switched to lunchtime barbecues outside, which made a big difference for all of us, especially until their children outgrew their swing, and it was taken down. During lunch, we would take turns pushing our daughter on the swing, and sitting eating with family. She would not eat with anyone else around, so she mainly ate at home. Entertaining at home was often easier, as although friends were empathetic they did not necessarily understand the challenges of going out to homes with

breakables within easy reach. When our daughter was younger she liked the sound of clinking two glasses together, particularly the musical sound of crystal.

Wanting to be able to watch my second daughter play netball, and realising my daughter with ASD would not know that this game did not include her, I decided to park in the school grounds back from the court so that I didn't miss out watching the game. Knowing our situation, other parents understood why I sat in a car with my daughter bouncing around in the back seat listening to her favourite songs, with childproof locks on. Unless my daughter with ASD was in respite care, my husband and I could not both attend our other daughter's school functions, or go out together with her, which was disappointing.

Financial Issues

Families in economically distressed cities or countries often face extreme financial challenges. This is further exacerbated in families including a member with a disability. In a recent study across 14 countries, Brown (2012) reported that financial stability was an important factor that substantially contributed to or detracted from FQOL. This is concerning, as having a child with a disability usually impacts the employment decisions families make (or are forced to make). Brown, Geider, Primrose, and Jokinen (2011) noted that in many families where there is a child with a complex and severe disability, one or both parents might change their work or give up work in order to care for the child. This can lead to financial constraints and increased self-dependence, which restricts social and economic opportunities for all family members and limits resources for their family member with a disability. The FQOL principle of holism stresses the interconnectedness of life domains such as income, health, recreation, and community relations; when one domain is negatively impacted this can have a domino effect on other life domains such as financial and emotional well-being.

In the many years I have worked with families including a person with disability, I have encountered many distressing circumstances. Families in financial need having to choose between providing basic resources such as food, clothing, and shelter for their entire family or providing medication or services for their child with a disability. Some single mothers I have met had to survive on social security benefits, rarely with any financial support from their son or daughter's father. Many were in rental accommodation, unable to afford modifications to improve the living situation, and without enough space to manoeuvre a wheelchair, let alone a portable lifter. A worrying number of mothers had partners leave because of the child with special needs. Some had more than one child with disability, and were even more financially stretched trying to manage on social services. Many lived in the outer suburbs where accommodation was cheaper, but without a car; transport and food were thus often more expensive, and accessing appropriate medical and disability services was more difficult. Although caring for my daughter was very challenging with recurrent hospitalisations, severe medication reactions, and unexplained episodes of illness, we were in a better situation than many of the parents I saw.

Summary and Concluding Comments

To improve HRQOL for people with IDD, and therefore HRFQOL, the most important requirement is for health and disability clinicians to recognise that the person with IDD is the central person about whom they should all revolve as a collaborative team. For many people with IDD and their families it feels as if the person with IDD is on the farthest edge of the circle, sometimes considered more an “interesting case” than a person. The reader may think there is too much focus on children and young people with ASD in this article, but in my experience a high proportion of the children and young people I saw with challenging behaviours had ASD. Their families were coping with many major issues not only in terms of health needs but also behavioural difficulties, and challenges finding appropriate support services.

It is easy for the reader to assume that any individual family in which there is a person with IDD has only occasional issues and stresses to cope with, that life is generally plain sailing and predictable, and that positive experiences occur without any effort on the part of the family members. One might also think it improbable that more than one of the vignettes would apply to an individual family. Although some issues have been described individually for clarity, the reader should be cognizant of the fact that families are often coping concurrently with many of the situations described. Although names have been left out for privacy purposes, each vignette either relates specifically to one individual person with IDD or was collated from the similar experiences of a number of individuals. Some vignettes are actual descriptions of family life with the author’s now-adult daughter, illustrating the complexities of having a person with IDD, autism, and severe epilepsy in the family. Although the vignettes are true in every detail, the reader could be forgiven for dismissing them as far-fetched. Ours is not the only family supporting a person with disability and complex health needs; such events occur in many other families. I hope the information in this article will provide greater insight for therapeutic, education, and other support staff, as well as clinicians, in supporting such families. The impact of HRFQOL issues on the person with disability and the family, including siblings, is often significant, but all are entitled to the support they need to enhance their FQOL.

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