Parenting a Child with Intellectual Disability – Factors That May Contribute in Making Parenthood a Positive Experience

Elvira Psaila
University of Malta, Imsida
elvira.spiteri@gmail.com

DOI: 10.17774/CDJ1.32016.5.20575874

Disability and the Family
Publication Date: 15 October 2016

The Considering Disability Journal is a student and graduate led-peer reviewed academic publication in the field of Disability Studies.

Considering Disability CIC
InTechnology Enterprise Incubation Centre
Suite S1B, Leeds Innovation Centre
103 Claredon Road, Leeds
LS2 9DF
United Kingdom

Volume 1: Issues 3&4
ISSN (Print): 2057-5874

Parenting a Child with Intellectual Disability – Factors That May Contribute in Making Parenthood a Positive Experience

Elvira Psaila

Abstract

Parents / guardians can be the most important persons in any child's life, and their approach to the promotion of autonomy and independence has a direct effect in the present and future quality of life of their children (Cardona 2013, Devenney 2004). The parents' approach is dependent on a number of intrinsic factors, including qualities in their personality and external factors. This paper reviews both internal and external factors, as present in literature, which can determine how parenting a child with an intellectual disability can be a positive experience. One in which the parents act as enablers in creating an environment that promotes the development of their children into autonomous adults from the moment of disclosure of the presence of intellectual impairment. The paper reviews literature that explores coping mechanisms, resilience and sense of coherence (SoC) as intrinsic qualities, and working with professionals and support systems as external factors. In conclusion, through my experience and from the literature read, for parents to be enablers in the child's life, a number of internal and external factors must play together. Although strength of character is required from the parents, adequate formal and informal support systems must be available.

Introduction

> When you're having a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books and make your wonderful plans…. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland".

(Kingsley 1987 pp1).

This was how Emily Perl Kingsley (1987) describes her experience of having a son with Down syndrome. It is not what the parents are expecting, however, Kingsley (1987) continues by emphasizing that although different and unexpected,

> they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place

(Kingsley 1987, pp1).

The ability for parents having a child with an intellectual disability to reach this conclusion may not be an easy and straightforward journey. But by embracing such a frame of thought, it may facilitate the ability of the parents to act as enablers in providing their child with the tools necessary to grow into an independent and autonomous adult. Failure to view parenting a child with an intellectual disability in such a manner may result in the creation of a barrier-full environment that hinders full, holistic development of the child.

For the purpose of this paper, the term parents also encompasses the role played by guardians caring for children not living with their biological parents. Furthermore, although the voice and experience of the children themselves is of utmost value and importance, this paper focuses solely on the experience of parents having a child with intellectual disability as present in literature. The skills, factors and tools which are necessary to help view parenting a child with intellectual disability in a positive manner from the moment of disclosure are therefore explored. It must also be noted, that my experience as a physiotherapist working with children with disability on a daily basis has also influenced my discussion.

Society's Expectations of Persons Having an Intellectual Impairment

Globally, it is estimated that approximately 1% of the general population has an intellectual impairment (Maulik et al 2011). Of these, approximately 85% of persons having an intellectual disability, have a mild impairment, about 10% are estimated to have moderate impairment, 4% with severe impairment and 2% having profound intellectual impairment (Maulik & Harbour 2010). Studies also show that there is a higher prevalence of intellectual disability in males, and in low socio-economic families (Maulik & Harbour 2010).

Having a disability can riddle one's life with a number of stereotypes (Barnes 1997) and having an intellectual disability is linked to various stigmas dating back to ancient times. Persons with intellectual disabilities are often said to have been left roaming around the village, and commonly referred to as the village fool or hidden away in family farms and cellars (Barnes 1992, Devenney 2004, Camilleri, 2006). Although nowadays more opportunities are available for persons with intellectual disabilities, and they are no longer confined to cellars or to ridicule by the whole village, such portrayals have led to the development of stigmatised attitudes towards persons with intellectual disabilities. Such stigma can take various forms, ranging fqrom discrimination and abuse, to overprotection and therefore denial of opportunities for autonomy and independence (Beart, Hardy, & Buchan 2005, Cooney, Jahoda, Gumley, & Knott 2006; Jahoda, Cattermole, & Markova 1989 as cited in Jahoda et al 2010).

Such attitudes will also affect the parents of persons with intellectual disabilities. Parents are aware of the stereotypes present in society and this may affect their attitude towards their child. This may result in either overprotection, in order to attempt to shield the child from such negative perceptions, to feelings of shame and possibly guilt.

Breaking the News

In their personal narratives, both Nia Wyn (2008) and Jennifer Graf Groneberg (2008), mothers of child with cerebral palsy and Down syndrome respectively, describe discovering that their child had a disability as like *'death'*. So how do parents balance the '*loss of a "perfect" baby'* (Wright 2008) and re-shape the hopes, dreams and aspirations they had for their child (Graungaard & Skov 2006), and still see parenthood in a positive way?

A study in 2002 by Heiman showed that on disclosure of impairment, the majority of parents exhibit a negative emotional response similar to that of the above mentioned mothers, and that parents generally undergo a bereavement process (Tanti Burlò 1992). As this paper is discussing parents having children with an intellectual disability, the impairment and its severity, may not be detected immediately at birth, unless associated with a specific condition or syndrome. Studies, however, agree that whether disclosure occurs shortly after birth, or at a later stage in the child's life, a number of factors will influence the parents' experience and emotions (Hasnat & Graves 2006, Graungaard & Skov 2006, Wright 2008). Setting, timing, words used, information and support given (Wright 2008) are all factors that influence parents' satisfaction, or dissatisfaction, with the way the disability is disclosed to them, and subsequently their outlook on their child’s future (Hasnat & Graves 2006, Hasnat & Graves 2000, Graungaard & Skov 2006, Taanila et al 2002, Sloper & Turner 1993). Ideally, the news is delivered in a private setting, with the least number of medical professionals present (Wright 2008) and as shortly as possible following any diagnostic tests or assessments required (Wright 2008). Unfortunately, from the personal experience of clients I work with, and from literature, very often this does not happen. More often, news is given in a hospital room, in the presence of medical students, relatives and other patients (Wright 2008), or realisation by the mother occurs as the expression of the medical staff changes or they even start crying on delivering the baby, and information is sometimes withheld, causing a sense of ‘*impending doom’* (Wright 2008).

On the other hand, if it is the parents who are suspecting that an intellectual impairment may be present, they might have prepared themselves better for the actual confirmation of the presence of the impairment. This adheres to the findings of the 2006 study by Hasnat and Graves, which shows that parents of older children fared better with the disclosure of their child’s disability, and, that if the parents themselves suspected the presence of an impairment first, they even felt relief on the acknowledgement of a diagnosis (Hasnat & Graves 2006).

The medical professional delivering the news also has a crucial role in the parents’ response. Although it is acknowledged that conveying the news that an impairment is present to parents is by no means an easy task (Graungaard & Skov 2006), Hasnat and Graves (2000) report that in their study, only 51% of professionals felt comfortable being frank in delivering news of the presence of intellectual impairment. The pediatricians involved in the above mentioned study, also report that they shape their disclosure on a number of characteristics present in the child’s parents, including their level of education and emotional standpoint

(Hasnat & Graves 2000). This contrasts with what the parents expect, as studies have shown that parents expect to be given all the information available, and prefer feeling overwhelmed by the amount of information given (Wright 2008, Hasnat & Graves 2006, Graugaard & Skov 2006). Medical professionals also tend to use words that highlight the disability, creating a sense of tragedy and taking away the joyous experience of parenthood (Wright 2008, Graungaard & Skov 2006). This could stem from the professionals' belief that *'detachment is part of being professional'* (Hasnat & Graves 2006), whereas parents feel better if the medical professional shows empathy and understanding (Graungaard & Skov 2006). This shows that, if adequately trained in breaking the news to parents, medical professionals can be instrumental in curbing the level of shock and in helping the family develop positive attitudes towards their child (Tanti Burlò 1992).

Moving On

Once the parents are informed of their child's impairment, the journey of parenthood resumes, probably through a different route than that envisaged by the parents (Graf Groneberg 2008, Kingsley 1987). This entails the parents to use a number of internal and external resources in order to move forward (Taanila et al 2002). Hence, a number of concepts and personal traits are put to the test at this stage, and these include coping skills, resilience and sense of coherence.

Coping

'Coping' is defined by Lazarus and Folkman (1986) as the ability to change and challenge a *'troubled person-environment relationship'* and the ability to *'regulate emotional distress'.* Coping is therefore an active process, using both behaviour and resources, to manage stressful situations (Taanila et al 2002). As shown by Graungaard and Skov (2006), parents of children with disabilities adopt both problem-focused coping strategies and emotional coping strategies. Problem-focused mechanisms include collecting information and new remedies, possibly including interventions which have not been approved scientifically, learning new skills and training opportunities, controlling medical professionals' actions and seeking second opinions (Graungaard & Skov 2006). Strategies adopted to help cope emotionally attempt to bring out a positive experience by creating future images and possibilities for the child and retaining hope, through the search and help of social support and possibly by ignoring the extent of the impairment (Graungaard & Skov 2006).

Gathering information and feeling adequately informed about the child's diagnosis played an important role in families (of persons with intellectual disability) that studies found to be coping well (Graungaard and Skov 2006, Taanila et al 2002). Having a good knowledge of the child's condition enabled the parents to form a more positive outlook for the child's future (Taanila et al 2002). Support systems also play an important role in the family's ability to cope. These may include both familial support, such as from the extended family and friends, or, from social and welfare support systems (Taanila et al 2002).

Another important coping skill targets the emotional well-being of the parents. Namely, the ability to talk openly about one's emotions and taking time to take care of oneself, through activities or hobbies the parent enjoys, or through meeting with friends (Taanila et al 2002). A study by Taanila et al (2002) showed that the main differences between high-coping and low-coping families of children with intellectual disability were indeed the above-mentioned factors, namely the parent's reaction to their child's diagnosis, the family values, and the level of formal and informal support.

Resilience

Closely linked to the ability to cope is the concept of resilience. Resilience is defined by Heiman (2002) as *'the ability to withstand and rebound from crisis and distress'*. Studies have shown different factors which compose and reinforce resilience in a person, and these include the ability to reshape barriers and obstacles, self-efficacy and faith (Bachay and Cingel 1999 as cited in Heiman 2002). Although, as mentioned, disclosure of the presence of a disability is often likened to bereavement and is considered as a negative experience by most parents, families can either deny the presence of the impairment, or adopt an ineffective, rigid reaction, or, be flexible and engage in positive, effective action (Falik 1995 as cited in Heiman 2002). The latter are the families and parents which show resilience. Thus, resilience can be said to allow for a positive psychological state, despite adverse situations (Olsson & Hwang 2008).

Resilience is an interactive process (Olsson & Hwang 2008), gained through the parents' ability to view the child having the impairment in a holistic and positive manner (Heiman 2002). This is achieved by viewing the child as an equal part of the family, believing that the child has a right to live like other children, and by seeking the necessary support. The study conducted in 2002 by Heiman showed three main factors required for resilient functioning within the family – the ability to openly discuss and consult professionals and family, a positive bond between the parents and a variety of support systems, targeting all the family's needs. Still, it must be kept in mind that:

> resilience does not mean bouncing back unscratched, instead, it reflects the abilities of struggling parents and their learning from adversity.
>
> (Margalit & Kleitman 2006 pp 271)

Sense of Coherence

Closely linked to coping and resilience is the idea of Sense of Coherence (SoC), developed by Antonovsky (1979) in his salutogenic theory. SoC is based on factors that ease the movement to well-being (health-ease) (Oelofsen & Richardson 2006) and is explained as:

> The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring through dynamic feeling of confidence that: (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands

> posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement
>
> (Antonovsky 1987, pp19).

A strong SoC is developed when an individual is able to create meaningfulness, manageability and comprehensibility from the stressors he/she is faced with (Oelofsen & Richardson 2006, Margalit & Kleitman 2006, Mak, Ho & Law 2006). Individuals with a high SoC are capable of challenging stressful situations by being more resourceful and flexible, and by being more emotionally and cognitively equipped to identify and confront problems than persons with a low SoC (Pisula & Kossakowska 2010).

The concept of SoC has been applied to parents who have children with disability in a number of studies. Studies tend to all show that parents of children with intellectual disability have lower SoC levels than parents of non-disabled children used in control groups. Such results were obtained in studies by Oelofsen & Richardson (2006), Margalit & Kleitman (2006), Mak, Ho & Law (2006), Pisula & Kossakowska (2010) and Olsson and Hwang (2002). This leads to the question of how having a child with intellectual disability affects SoC.

According to Olsson and Hwang (2002) it can be argued that having a child with intellectual disability directly threatens the fundamental concepts of SoC, i.e. comprehensibility, manageability and meaningfulness. Comprehensibility may be threatened through lack of accurate, clear and accessible information (Olsson & Hwang 2002). High caring demands, or services which are difficult to access make the sense of manageability more difficult for parents (Olsson & Hwang 2002), and not being able to pursue personal needs, interests and goals threatens the concept of meaningfulness (Olsson & Hwang 2002). Such factors can change parenthood into a highly negative experience (Olsson & Hwang 2002), and consequently affecting the quality of life of the child.

Support Systems

As previously discussed, the process of enabling a positive outlook on parenting a child with intellectual disability requires both internal and external resources from the parents. The internal resources, which were introduced above, cannot reach full effect without a solid network of support systems, both formal and informal, in ensuring the children have the right tools to develop into autonomous, self-determined adults.

Informal systems include the ability of the parents to work together in dividing household chores, raise their children, and dedicate time to each other and themselves. Siblings also play an important role, and can offer invaluable support both to the parents and to their sibling. It is however also important, that in childhood the siblings are not made to feel like the main carers, taking away from their own individual experience of childhood. The reality however, is that as the person with intellectual disability grows up, inevitably so do the parents and the responsibility for caring may fall onto the siblings. This continues to highlight the need that the person with intellectual disability is as independent and self-sufficient as possible. Other important family members that can help facilitate and help the parents in daily life, are the grandparents and other members of the extended family. In the absence of, or besides, the family may also receive help from family friends.

On birth, or on diagnosis, the family may enter a formal network of support. This may range from support from parent-run groups or NGOs to service-givers. Meeting other parents having children with the same disability can be of great help to parents who have just received their child’s diagnosis, as they can advise on a variety of strategies and instill hope in the parents (Graf Groneberg 2008). As the child with intellectual disability reaches adolescence and adulthood, different support services are required. Private NGOs do offer programs that enhance and promote life skills and the ability to care for one’s self. Respite is another support service which parents might find useful, although from experience, parents tend to harbor feelings of guilt when using such a service.

As can be seen, formal support services can also emphasize the different models of disability. Services can be medically-oriented, and target the achievement of age-appropriate milestones in various aspects of the child’s life. NGOs might offer an alternative approach, through programs such as home-based early intervention, school support and through programs designed to provide adolescents and youths having an intellectual disability with tools which can be used in everyday living to be as independent as possible, thus highlighting the Capabilities Model. NGOs that bring parents together may reinforce the Social Model by creating awareness and hence challenge attitudinal barriers created by society. The services the parents opt for can therefore be influenced by their own approach to how disability is viewed. Parents’ right to ‘shop around’ for different services might provide a mixture of approaches towards disability, and although this has its benefits, it is also important that the child’s life is not made to revolve around such services, taking away from the child’s right to have a normal childhood which includes play with peers in an inclusive environment.

Working with Professionals

Achieving developmental milestones may take longer in children with intellectual disability, thus, a number of different therapies, such as physiotherapy, occupational therapy and speech and language therapy may be required. This entails that the parents may need to change their daily routine, and possibly require changes in their working times, adding further concerns and stresses to their everyday life. The adaptability of the parents to these required changes, will all directly affect the opportunities made available for the child to develop into an autonomous adult. Besides the parents' ability to adapt to the new challenges a life with a child with intellectual disability presents, the parents' philosophy on how professionals are to work with the child is also of importance.

Parents expect to have an active role in the care of their child (Wright 2008, Graungaard & Skov 2006), and this may be achieved through the approach taken by the professionals involved, preferably as asked for by the parents. If a multidisciplinary approach is taken, although there is the possibility of consultation, different professionals are expected to stay within their own professional realm (Choi & Pak 2006), with little or no overlap over the work done by the other professionals involved. This may result in multiple appointments in different settings, with professionals working with different approaches with the same child, and possibly blurring the parents' judgment on what is the best approach for their child. A more interactive approach which can be implemented is an interdisciplinary approach, whereby the links and overlaps between different professions are synthesized into *'a coordinated and coherent whole'* (Choi & Pak 2006). In order for the child to receive the most holistic care possible, however, ideally a transdisciplinary approach is used. In a transdisciplinary approach, '*natural, social and health sciences in a humanities context, transcend their traditional boundaries'* (Choi & Pak 2006). This implies that the parents are equal partners with all the professionals involved, and that different interventions (medical, educational and social) may be combined in ways which best suit the needs of the individual child.

Unfortunately, in services offered, particularly by the State, such an approach (transdisciplinary) is not always offered. Professionals, from my own personal experience, tend to prefer to stick to the confinements of their profession, and it requires self-determination and insistence by the parents to push the professionals to challenge their traditional roles. This attitude is present both in a clinical and educational setting, and most parents I work with, still tend to keep back from challenging professionals for fear that it might negatively affect the service provided to their child.

Students with intellectual disabilities are increasingly attending mainstream education (Camilleri 2012) particularly at primary school level, although the percentage rises at secondary school level (German 2013). This could be attributed to the use of Learning Support Assistants (LSAs) and Individualized Educational Programs (IEP) in mainstream classrooms. Although IEPs are intended to listen to the student and the parents and create a program centered round the child's individual needs, from personal experience this is not always the case, with teachers and professionals talking and deciding over the child and parents. In a qualitative study by German (2013), the majority of parents interviewed experienced negative attitudes towards their child in mainstream primary schools, resulting in the parents who had most negative experiences to opt for resource centers for their child at secondary school level. Thus it seems that although literature reinforces the idea that parents know their children best and should be active co-partners with the educators in their child's life (Mohsin et al 2011, Snell & Brown 2006), this is not being put into practice. One must therefore question whether it is the parents who lack the internal resources and appropriate support systems to feel confident in being powerful advocates for their child’s inclusion, or whether professionals lack the empathy and the ability to acknowledge parents as their equals in the child’s education.

Mothers & Fathers – Different or Same?

Although parents to the same child, and disclosure of the presence of an impairment is generally given to both parents at the same time, studies have reported a number of differences between mothers and fathers in their reactions and strategies adopted to adapt to the news. According to a study by Graungaard and Skov (2006), such differences may be visible upon disclosure of the impairment. Graungaard and Skov (2006) reported that whilst mothers focused on caring for the child and embracing parental duties, fathers wanted a clearer picture of what the child's future would be like. On disclosure, the same study showed that fathers preferred having written, scientific information regarding their child's disability in order to better understand and cope (Graungaard & Skov 2006). This contrasted with the mothers' reactions, whereby at this initial stage they were unable to process such detailed information (Graungaard & Skov 2006). The initial reaction of both parents has been linked to the family's ability to cope as the child grows up. Equal acceptance of the child by both parents facilitates coping, leading to better coping skills within the whole family unit (Taanila et al 2002). On the other hand, families in which the father had difficulty in accepting the child's disability were found to have lower coping abilities than the families in which both parents were equally accepting of the disability (Taanila et al 2002).

Studies also agree that having a child with intellectual disability has a more significant effect on the mother (Wright 2008). The study by Tanti Burlò (1992) on parents having a child with an intellectual impairment attending a special school in Malta, had similar results, with 10% of mothers interviewed said to have a psychiatric condition, in comparison to only 4% of the fathers. The fact that it is often the mother who gives up her job and career in order to care for the child (Wright 2008) coupled with the responsibilities of managing the household, possibly with less income (Hastings 2003, Wright 2008) may all contribute to further anxiety in mothers than in fathers (Hastings 2003).

Having the mother as the main carer may also explain the difference in what the parents experience as the main stressors in relation to having a child with intellectual disability. According to Salovita, Italinna and Leinonen (2003), the main stressor for mothers are behavioural problems, thus, mothers having children with intellectual difficulties coupled with behavioural difficulties have a higher level of stress then mothers whose child, despite having an intellectual impairment, does not exhibit any behavioural problems.

For fathers, however, the principle stressor is the social isolation and exclusion faced by their children and possibly the entire family (Salovita, Italinna and Leinonen 2003). Although the study by Salovita, Italinna and Leinonen (2003) found that fathers are mostly affected by societal implications, a study by Ricci and Hodapp (2003) showed that the relationship of fathers with their child having an intellectual disability is also dependent on factors such as behavior and character disposition. Their study showed that although equally involved in caring for the child, fathers of children with Down syndrome had a much more positive outlook than fathers of children with other forms of intellectual disability (Ricci & Hodapp 2003). This has been linked to the results of studies whereby parents, that is both mothers and fathers, have described their child with Down syndrome in positive terms, such as sociable, affectionate and cheerful (Wishart & Johnston 1990 and Hornby 1995 as cited in Ricci & Hodapp 2003). Similar results were obtained in a study by Dabrowska and Pisula (2010), where parents of children with Down syndrome had lower stress levels than parents of children with autism. The same study, also showed results similar to those of Wright (2008), where mothers of children with autism had higher stress levels than the fathers (Dabrowska & Pisula 2010).

Besides the individual effect on the parents, having a child with a disability affects the relationship between the parents themselves and towards any other children in the family. Literature tends to deduce that having a child with a disability negatively affects the family dynamics and relationships. However, a study by Risdal and Singer (2004) suggests that this detrimental effect is much lower than expected.

Bringing It All Together

Parents can be the most important and influential persons in any child’s life, and their approach to the promotion of autonomy and independence has direct effect on the present and future quality of life of their children (Cardona 2013, Devenney 2004, Younis as cited in Hunt 1966). As discussed, the parents’ approach is dependent on a number of factors, including qualities in their personality and external factors. The higher prevalence of persons having intellectual disabilities in families with lower socio-economic status (Maulik & Harbour 2010) may mean that these families have less resources available to them, as, as mentioned in the support services available, those offered by the State are mainly targeted at achieving developmental milestones, and thus, the parents’ needs may not be addressed holistically. Although some parents may not be financially able to provide their child, and themselves, with extra support services from private entities, parents can still be powerful advocates in ensuring that their children are able to reach their full potential.

Such advocacy may take place in a variety of settings, ranging from the clinical to the classroom. Studies have shown that parents of children with intellectual disabilities expect to be co-partners with the medical professionals in their child’s life (Wright 2008 and Graungaard & Skov 2006), however, often parents given incomplete information. From my personal experience working with children as a physiotherapist, parents often leave doctors’ offices with unanswered questions, with their hopes dashed and feeling at a loss. Most parents I work with are unaware of what services and support systems are available, and may end up believing incorrect information gathered from unreliable sources off the internet.

The same holds true for the education system. Although by law all children have a right to an equal, inclusive education (UNCRC 1989), literature shows that educators are more receptive and accepting of children with physical impairments and feel inadequately trained to teach students with intellectual impairments in mixed-ability classes (Center & Ward 1987, Soodak, Podell & Lehman 1998 and Avramidis & Norwich 2002). Parents may therefore be pushed, or encouraged, to send their children to special schools. Standing ground, and insisting that the child starts / continues mainstream education requires the parents to make full use of their internal resources, and ensure that they have the emotional support and backing required from family and friends and other professionals.

In my opinion, through my experience and from the literature read, for parents to be enablers in the child's life, a number of factors must play together. Better support is required from State-provided services, possibly through monitoring of the family along the life course, so as to suggest on appropriate services and provide the parents with the support needed as their needs change over time. Although strength of character is required from the parents, professionals, family and friends in contact with the family, must allow the parents to feel that it is fine to feel scared and vulnerable. Professionals must accept that parents know their children better than anyone and no child is a textbook 'case', parents have a right to be consulted and there is nothing wrong in showing empathy and allowing for hope. And in conclusion, again using the words of Emily Perl Kingsley (1987), parents must be guided to realize that

> if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things…. About Holland.

References

Ali, A., Strydon, A. & Williams, R. (2008). A Measure of Perceived Stigma in Persons with Intellectual Disability. In *Journal of Psychiatry,* 183, pp 410-415

American Association of Intellectual and Developmental Disabilities (2013). *FAQs on Intellectual Disability.* Retrieved from http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability

American Psychiatric Association (2013). *Intellectual disability.* Retrieved from http://www.dsm5.org/documents/intellectual%20disability%20fact%20sheet.pdf

American Psychiatric Association (2013). *Highlights & Changes from DSM-IV_TR to DSM-5.* Retrieved from http://www.psych.uic.edu/docassist/changes-from-dsm-iv-tr-to-dsm-51.pdf

Avramidis, E. & Norwich, B. (20002). Teachers' Attitudes towards Integration / Inclusion: Review of the Literature. In *European Journal of Special Needs Education* 17(2), pp 129-147

Barnes, C. (1992). *Disabling Imagery and the Media – An Exploration of the Principles for Media Representations of Disabled People.* Retrieved from http://www.leeds.ac.uk/files/disability-studies/archiveuk/Barnes/Coalition.pdf

Barnes, C. (1997). A legacy of Oppression: A History of Disability in Western Culture. In Barton, L. & Oliver, M. (Eds.), *Disability Studies: Past, Present and Future.* Leeds: The Disability Press, pp 3-24

Barnes, C. (2003). *Effecting Change: disability, Culture & Art?* Retrieved from http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/Effecting%Change.pdf

Bellanca, N., Biggeri, M. & Marchetta, F. (2011). An Extension of the Capability Approach: Towards a Theory of Dis-capability. In *European Journal of Disability Research,* 5, pp 158-176

Camilleri, I. (2012). *Malta praised for its special needs integration.* The Times of Malta. Retrieved from http://www.timesofmalta.com/articles/view/20120711/local/Malta-praised-for-its-special-needs-integration.428039

Camilleri, J. (2006). *The Genesis of Disability Studies in Malta: From a Colonial Post to an Independent Future?* Retrieved from http://www.knpd.org/pubs/opus/0609_lancaster_camilleri.pdf

Center, Y. & Ward, J. (1987). Teachers' Attitudes Towards the Integration of Disabled Children into Regular Schools. In *The exceptional Child,* 34(1), pp 41-56

Choi, B.C.K. & Pak, A.W.P. (2006). Multidisciplinarity, Interdisciplinarity and Transdisciplinarity in Health Research, Services, Education and Policy: 1. Definitions, Objectives, and Evidence of Effectiveness. In *Clin Invest Med* 29(6), pp 351-364. Retrieved from http://courseweb.edteched.uottawa.ca/pop8910/PDF%20Files/Choi_Multidisciplinary.pdf

Dabrowska, A. & Pisula, E. (2010). Parenting Stress and Coping Skills in Mothers and Fathers of Pre-school Children with Autism and Down Syndrome. In *Journal of Intellectual Disability Research,* 54(3), pp 266-280

Darwin, C. (1871). *The Descent of Man.* US: D. Appleton & Company

De la Rocha, K. (2013). *Intellectual Disability.* Retrieved from http://pediatrics.med.nyu.edu/conditions-we-treat/conditions/intellectual-disability

Devenney, M.J.V. (2004). *The Social Representations of Disability: Fears, Fantasies and Facts.* Retrieved from http://www.leeds.ac.uk/disability-studies/archiveuk/devenney/PhD%20Final%20_including%20bibiliography_.pdf

Equal Opportunities Persons with Disability Act (2000). *Cap 413.* Retrieved from http://www.mita.gov.mt/MedicalCenter/PDFs/1_article20110004_equalopportunitiesact.pdf

Finkelstein, V. (2001). *A Personal Journey into Disability Politics.* Retrieved from http://www.independentliving.org/docs3/finkelstein01a.pdf

Ford, C. (2011). *High on Aspiration, Low on Implementation: the Development and Implementation of the New Zealand Disability Strategy.* Retrieved from otago.ourarchive.ac.nz

German, N. (2013). Education for Children with Intellectual Impairment: Parents' Perspectives

Geyer, S. (1997). Some Conceptual Considerations on the Sense of Coherence. In *Social Science & Medicine,* 44(12), pp 1771-1779

Graf Groneberg, J. (2008). *Roadmap to Holland: How I Found My Way through My Son's First Two Years With Down Syndrome.* USA: New American Library

Graungaard, A.H. & Skov, L. (2006). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. In *Child: Care, Health and Development,* 33(3), pp 296-307

Groholt, E.K., Stigum, H., Nordhagen, R. & kohler, L. (2003). Is Parental Sense of Coherence Associated with Child Health? In *European Journal of Public Health,* 13(3), pp 195-201

Harnacke, C. (2013). Disability and Capability: Exploring the Usefulness of Martha Nussbaum's Capabilities Approach for the UN Disability Rights Convention. In *Journal of Law, Medicine & Ethics,* 41(4), pp768-780

Harris, C.J. (2013). *New Terminology for Mental Retardation in DSM-5 and ICD-11.* Retrieved from http://www.medscape.com/viewarticle/782709

Hasnat, M.J. & Graves, P. (2000). Disclosure of Developmental Disability: A Study of Parent Satisfaction and the Determinants of Satisfaction. In *Journal of Pediatrics & Child Health,* 36, pp 32-35

Hasnat, M.J. & Graves, P. (2000). Disclosure of Developmental Disability: A Study of Pediatrician Practices. In *Journal of Pediatrics & Child Health,* 36, pp 27-31

Hastings, R.P. (2003). Child Behavior Problems and Partner Mental Health as Correlates of Stress in Mothers and Fathers of Children with Autism. In *Journal of Intellectual Disability Research,* 47(4-5), pp 300-312

Heiman, T. (2002). Parents of Children with Disabilities: Resilience, Coping and Future Expectations. In *Journal of Developmental and Physical Disabilities* 14(2), pp 159-171

ICD-10 (2010). *Chapter V – Mental and Behavioural Disorders.* Retrieved from http://apps.who.int/classifications/icd10/browse/2010/en4/F70-79

International Classification of Functioning (ICF) (2014). Retrieved from http://apps.who.int/classifications/icfbrowser/

Kingsley, E.P. (1987). *Welcome to Holland.* Retrieved from http://www.our-kids.org/archives/Holland.html

Jahoda, A. et al (2010). Living With Stigma and the Self-Perceptions of People with Mild Intellectual Disabilities. In *Journal of Social Issues,* 66(3), pp 521-534

Lazarus, R.S. & Folkman, S. (1987). Transactional Theory and Research on Emotions and Coping. In *European Journal of Personality,* 1, pp 141-169

Mak, W.W.S., Ho, A.H.Y. & Law, R.W. (2006). Sense of Coherence, Parenting Attitudes and Stress among Mothers of Children with Autism in Hong Kong. In *Journal of Applied Research in Intellectual Disabilities,* 20(2), pp 157-167

Margalit, M. et al (1988). Social-environmental Characteristics (Family Climate) and Sense of Coherence in Kibbutz Families with Disabled and Non-disabled Children. In *European Journal of Special Needs Education,* 3(2), pp 87-98

Margalit, M., Raviv, A. & Ankonina, D.B. (1992). Coping and Coherence Among Parents with Disabled Children. In *Journal of Clinical Child Psychology,* 21(3), pp 202-209

Maulik, P.K. & Harbour, C.K. (2010). Epidemiology of Intellectual Disability. In *Encyclopedia of Rehabilitation.* Retrieved from http://cirrie.buffalo.edu/encyclopedia/en/article/144/

Maulik, P.K., Mascerhans, M.N., Mathers, C.D., Dua, T. & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies. In *Research in Developmental Disabilities,* 32(2), 419-436

Mohsin, M. N., Khan, T. M., Doger, A. H. & Awan, A. S. (2011). Role of Parents in Training of Children with Intellectual Disability. In *International Journal of Humanities and Social Science* 1(9). Retrieved from http://www.ijhssnet.com/journals/Vol._1_No._9_Special_Issue_July_2011/11.pdf

NSO, (2009). *International Day of Persons with Disabilities: 2008.* Retrieved from http://www.nso.gov.mt/statdoc/document_file.aspx?id=2637

Oleofsen, N. & Richardson, P. (2006). Sense if Coherence and Parenting Stress in Mothers and Fathers of Pre-school Children with Developmental Disability. In *Journal of Intellectual and Developmental Disability,* 31(1), pp 1-12

Oliver, M. (2004). If I Had A Hammer: The Social Model in Action, in Swain, J. Finkelstein, V., French, S. and Thomas, C. (Eds). *Disabling Barriers, Enabling Environments,* 2nd edition, London: Sage Publications Ltd, pp7-12

Olsson, M.B. & Hwang, C.P. (2002). Sense of Coherence in Parents of Children with Different Developmental Disabilities. In *Journal of Intellectual Disability Research,* 46(7), pp 548-559

Quintero, M. (2013). *DSM-5: Changes in Intellectual Disabilities and Mental Health Disorders.* Retrieved from http://www.txcouncil.com/userfiles/file/2013%20Conference/Changes%20in%20Classification%20ID%20and %20MI_TXcouncil_2013.pdf

Ricci, L.D. & Hodapp, R.M. (2003). Fathers of Children with Down Syndrome versus Other Types of Intellectual Disability – Perceptions, Stress and Involvement. In *Journal of Intellectual Disability Research,* 47(4-5), pp 273-284

Risdal, D. & Singer, G.H.S. (2004). Martial Adjustment in Parents of Children with Disabilities: A Historical Review and Meta-Analysis. In *Research and Practice for Persons with Severe Disabilities* 29(2), pp 95-103

Salovita, T., Italinna, M. & Leinonen, R. (2003). Explaining the Parental Stress of Fathers and Mothers Caring for a Child with an Intellectual Disability: A Double ABCX Model. In *Journal of Intellectual Disability Research,* 47(4-5), pp300-312

Schneider, M. & Hartley, S. (2003). *International Classification of Functioning, Disability & Health (ICF) and CBR.* Retrieved from http://www.asksource.info/cbr-book/cbraspart_08.pdf

Sloper, P. & Turner, S. (1993). Risk and Resistance Factors in the Adaptation of Parents of Children with Severe Physical Disability. In *Journal of Child Psychology & Psychiatry,* 32(2), pp 167-188

Special Olympics (2009). *Status and Prospects of Persons with Intellectual Disability.* Retrieved from http://www.specialolympics.org/uploadedFiles/LandingPage/WhatWeDo/Research_Studies_Description_Pages/Policy_Paper_Status_Prospects.pdf

Snell, M. & Brown, F. (2006). *Instruction of Students with Severe Disabilities*. USA: Pearson.

Soodak, L.C., Podell, D.M. & Lehman, L.R. (1998). Teacher, Student and School Attributes as Predicators of Teachers' Responses to Inclusion. In *Journal of Special Education,* 31(4), pp 480-497

Taanila, A. et al (2002), Coping of Parents with Physically and/or Intellectually Disabled Children. In *Child: Care, Health and Development,* 28(1), pp 73-86

United Nations Convention on the Rights if Children (1989). Retrieved from http://www.childrensrights.ie/sites/default/files/submissions_reports/files/UNCRCEnglish_0.pdf

UPIAS (1975). *Fundamental Principles*

Wright, J.A. (2008). Prenatal and Postnatal Diagnosis of Infant Disability: Breaking the News to Mothers. In *Journal of Perinatal Education,* 17(3), pp 27-32

World Health Organization (2014). *Definition: Intellectual Disability.* Retrieved from http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability

Wyn, N. (2008). *Blue Sky July.* Wales: Penguin books