Living with Down Syndrome

Manuel I. Guerrero
Roy I. Brown

Published by Kindle Direct Publishing
First Edition August 2019
Cover design Raúl Campero
Cover photograph Diego Running Downhill

Registro Público de Derechos de Autor (Mexico)
03-2019-080812193800-01 ISBN: 9781082060106
Seal: Independently published

LIVING
WITH DOWN SYNDROME

LIVING
WITH DOWN SYNDROME

Manuel I. Guerrero
Roy I. Brown
compilers

CIUDAD DE MÉXICO
2019

INDEX

Dedication to Cliff Cunningham (1941-2013)

Sadly when we were in the midst of writing this book Cliff Cunningham detected a cancer on the lung, an inoperable one. He was always optimistic and made light remarks on his disease: *"Hi everyone"* – he wrote to his friends a few days before his demise – "*So it looks like I can skip past the first exit* (he always was joking about being on the transit lane or taking the next exit). *I must also be the only person the UK who is delighted with the late Spring* (a particularly cold one that of 2013). *My favourite season waiting for me to emerge from 'chemo lethargy' and ready to enjoy the season. The phrase the 'sun always shines on the righteous' comes to mind!"*

He left in this book not only his wisdom, he left his optimism – the optimism for the future; the optimism for life.

We wrote this book with that optimism in mind. A child with Down syndrome has to face challenges, along with his family, sometimes big challenges. But if there is optimism there is a solution.

Cliff was indefatigable in his work with persons with Down syndrome. He followed a large group of children – one of the largest ever undertaken – from their early years to adulthood and rose high expectations with his findings.

Thank you Cliff.

Philip W. Davidson*

There are hundreds of books, handbooks, manuals, and guides written for parents or other relatives and friends of family members with Down syndrome (Ds). One only has to go to any literary search engine or local library to see the impressive array. Many of these works deal with techniques to teach young children with Ds motor skills, language and thinking skills. Others focus on providing support for their readers in seeking and finding services, while still others offer emotional support. Some works are written by professionals, some by lay persons, and most authors have had personal experience with a family member with Ds. So the choices are wide, the options voluminous, and the perspectives of the authors diverse. This is not surprising: Ds is one of the most common chromosomal disorders affecting humans, has been fully described since 1866 and otherwise known for centuries. So the demand for user-friendly guides has been and continues to be very strong.

Why choose and read this book then? I can think of three reasons. First, the book is broadly focused on the age span, providing information to parents, family members and carers of persons with Ds of all ages. This is very important since persons with Ds age earlier and may have to confront issues of aging more frequently than people with other kinds of intellectual and developmental disabilities. Also, life course variability among people with Ds is rapidly changing given scientific and clinical advances that have taken place over the past 10 to 20 years. This book provides a very good background on such advances and is written in a way that makes them easy to understand.

A second unique feature of the book is its blending of science with personal histories told by grandparents, other relatives and friends, as well as by parents. I found this aspect of the book

* Professor Emeritus in Pediatrics, Environmental Medicine and Psychiatry, University of Rochester School of Medicine and Dentistry; President, International Association for the Scientific Study of Intellectual and Developmental Disabilities

compelling and believe it makes the text more readable by a lay audience. It is no accident that these stories found their way into the narrative; three of the authors have children or other family members with Ds.

Third, and maybe most important, this book is only one of the very few works originally written with Spanish speakers for Spanish speakers. You are about to read a back-translation from Spanish to English. There is no doubt that Spanish language and culture are becoming part of the fibre of developed and developing countries worldwide; and the prevalence of Ds is no different in families of Spanish origin than it is in other cultures. So the need for this work is great and growing. Two of the four authors of the Spanish language version of the book are Mexican citizens while one of the two compilers of the English version is a Mexican citizen. They confer utter clarity and cultural relevance to the text.

I am very pleased to have been asked to write this foreword. As the book was being developed I got to know the lead author of the Spanish language version, Manuel Guerrero. I admire his attention to detail, his ability to write about complex subjects that renders them comprehensible, and the sensitive and wholesome way he and his co-authors have told the story of Ds. He and my friend Roy Brown have done a wonderful job compiling the English language version. This is indeed an important contribution.

Balbir Singh*

After 34 years of learning about, managing and living with Down syndrome alongside my daughter Jaspreet and our family, I was delighted when requested to pen a foreword for this book. Indeed, this is a refreshing book, and I am pleased to be well-acquainted with the excellent work of its dedicated authors. I am honoured and privileged to be a part of this worthy book.

I am glad that we have this quartet sharing with us the many facets of Down syndrome through this comprehensive

* Past President, Trustee, Down Syndrome International Advisor, Founding Chair, Down Syndrome Association, Singapore Facilitator, Asia Pacific Down Syndrome Federation Member of Numerous Disability Related Working Groups & Committees; Parent of Jaspreet, my primary reason of my numerous commitments.

book. I have known Roy for almost three decades, and during this time he has been a strong proponent for quality of life, always addressing this pertinent issue in his scholarly and persuasive manner. Roy has not only been a reliable friend but a mentor too. Rhonda, with her very endearing style, has always believed and promoted the notion that persons with Down syndrome can learn beyond their expectations; her daughter Ruth is a perfect example of her dedication to this cause! Being in their company is a learning and enriching experience for my family.

Through Roy and Rhonda, I have had the golden opportunity to get to know Manuel. His profound passion for wanting to do as much as he can for his grandson Diego has resulted in this treasure of a book!

I have come to know Gare Fabila through her writings, and I am indeed inspired by her tenacity. She is a mother of a child with multiple disabilities, and began her journey in 1970. Gare's tenacity comes across in a passage from the book, where she writes that she "has witnessed many changes, most positive yet slow, unequal, encountering that the difference lies in families with high spirits who have continually been pressing Society to change and develop in order to meet pressing needs." Her astute observations have been gleaned from her amazing and influential advocacy work.

All the authors have created a perfectly balanced collaboration that is complimentary of each others' varied wisdom and experiences, and which is peppered with the stories, anecdotes and experiences of some excellent contributors.

Succinctly voicing the feelings of every new parent, Manuel writes that "[a]cquiring information is a very important first step. That way many fears are dissipated. You realise you are not alone, and your case is one amongst many." How true, and how universal that the key to crossing the first hurdle is the availability of a good resource that both informs and provides us with comfort, becoming a companion to us as a coping mechanism. This book's friendly style and accessibility certainly fulfils all these characteristics, making it a truly excellent resource.

Down syndrome knows no borders. As the authors have written, "persons from many countries have contributed to this book, an example of what Down syndrome represents; no

geographical, ideological, political barriers - just a common purpose ."Through this theme which runs through the book, the authors have addressed varied international issues, including the United Nations Convention on the Rights of Persons with Disabilities, which outlines areas where the interests of persons with disabilities are to be protected throughout the world. The authors have underscored the many practical ways that this can be done in the field of Down syndrome across the life span.

All that we aim towards in all our efforts working for and alongside persons with Down syndrome is for their wellbeing and towards achieving a good quality of life. In this book, I am glad that issues relating to quality of life are well and appropriately addressed, relative to parallel issues. The authors also recognise that though many families are resilient support is frequently required, and the authors underline the many ways in which this needs to be achieved.

This is an excellent resource book; addressing a wide spectrum of issues while providing in-depth insight into key issues. It reaches out to a wider audience, beyond parents, grandparents, carers and friends. Indeed, educationists, health care professionals, therapists, students and many others will benefit greatly from reading it. It will be invaluable to enhancing their interests and rendering better care for persons with Down syndrome and their families as they will acquire deeper, first-hand knowledge and understanding of the many related challenges that persons with Down syndrome and their families face and need to overcome. Most of the information is based on personal and practical experience, as well as research, all presented with a global view.

The authors' collective and compelling sense of mission only gets stronger as you read on, strengthening their promotion of a better quality of life for persons with Down syndrome.

The stories from and of persons with Down syndrome put a face to the text, making us feel a part of their lives, and inviting us to share in their challenges, achievements, abilities and joys. In addition, the shared testimonies of families offers a different dimension, providing a holistic look at coping mechanisms borne out of having a child with special needs. This has been addressed very well, and will be a boon to the work that support groups do. These testimonies reflect the fears, hopes and aspirations

universally. It also clarifies the many myths and misinformation that surround the subject Down syndrome. Stories can be shared not just through words, but also through art. The paintings and art pieces portrayed throughout the book have provided a unique and valuable aspect to this book. The expressions reflected and feelings expressed offer a learning experience all of its own. It is brilliant addition that complements the prose.

I have found the book very inspiring, informative and most of all, heart-warming. As a parent, a volunteer and an advocate, I invite you on this journey too. Just read on and enrich yourself with the many experiences of others who are so willing to share.

My heartfelt appreciation to Manuel, Roy, Rhonda and Gare, as well other contributors, for their dedication to writing and compiling this excellent book.

Manuel shares this beautiful line with us, "I shall walk in life proudly with Diego." Manuel, I salute you, your co-authors, and the many others who work tirelessly for a better life for persons with Down syndrome.

Fernando del Río*

Some months ago Manuel Guerrero told me about the project to publish this book. It is a great initiative, valuable and opportune. The lack of trustworthy information is a great evil in many aspects of our society and Down syndrome (Ds) is no exception. Though indeed there are several million pages on the Internet about this subject just a tiny bit are in Spanish and with no commercial purpose. Besides it is difficult on the Net for those with little experience to discriminate the quality of the information found. The challenge faced by a family having one of its members with Ds, in itself a hard and difficult one in a society lacking organised support, is greatly enlarged by not having clear and reliable explanations on such condition or practical advice to overcome such challenge. For all the above reasons this book must be welcomed and its promoters and authors thanked in the name of those families.

---

* Emeritus and Distinguished Professor, Thermodynamics Laboratory, Departament of Physics. Universidad Autónoma Metropolitana, Iztapalapa. National Award in Sciences 2015

I must confess when Manuel approached me to write this foreword I was astounded, and though I felt honoured by the invitation my first reaction was to decline because of the stature and speciality of the authors of the other two forewords. Yet Manuel insisted and noted that I have a family experience – my brother had a profound intellectual disability – which gave me the proper sensibility. Besides I have editorial experience which could be useful. So I decided to accept.

This book has many virtues: clear explanations, plain language, an ample coverage of issues – few angles regarding persons with Ds are missing – substantial information and all this with a remarkable concision. However what impresses me most is its human warmth. This is accomplished by means of the many testimonies, not only of carers of children and adults but some persons with Ds as well. This abundance of real life examples, of concrete persons, confers the book warmth which will make its valuable information more understandable. A subject of particular relevance in my opinion is friendship in children and adults.

Immerse yourself in the life and avatars of a child with Down syndrome hand-in-hand with this book so you may share with Manuel how Diego, his grandson, showed him "a whole new world. Not exempt of sorrow but absolutely filled with human values, which are something to appreciate in a world at times lacking of them". This is what means taking a human being by what is essential and most valuable. It is thus that the open acceptance of a child with a disability has its rich and positive effects among the family members' relations.

It is to appreciate the fact that this book is the result of a group effort, as well as an example of international collaboration. The latter allows taking advantage of accumulated experience in countries where the attention to people with Ds has been for a long time very well organised. However being aware of the quality of services offered in more advanced societies only makes one wish to have in our countries at least something equivalent. Just by glancing at the bibliography that accompanies each chapter enables us to get a brief idea of how extensive the information is. It is a pity that the bibliography in Spanish is not as rich.

The book provides not only a deep comprehension of the challenges involved in caring for persons with disabilities but

valuable practical recommendations as well. It underlines the importance of quality of life for people with Ds, understood in the sense that everyone has to attain and make the things he himself decides. The centrality of this concept serves this book as a focal point.

Lastly, the explanation on how Down syndrome is a natural condition, a result of thousands of millions of years of evolution is not only splendid but puts things in its right perspective.

General Introduction
What does it mean to live with Down syndrome

Manuel I. Guerrero and Roy I. Brown

When my baby was born I
didn't know what to do
with her; now I don't
know what would I do
without her.
[A mother of a child with
Down syndrome]

The first of many questions

When a baby is born with Down syndrome a big turn in life is experienced – for the whole family. There are some who flee, not being able to cope with this situation but others, the majority, find new ways to continue living.

> "Somewhere along the process and being with parents of new babies every day I realised that in my face to face meetings we did not really start with logic and causes and chromosomes...the first questions by many parents were about would or how would they cope, what about the future, what to do, family members, feelings as well as why it happened." (Cliff Cunningham)

Would we be able to cope? It is certainly the first of many questions. There are others afterwards: would it become worse as the baby grows? Would she or he be able to play as any other child? What level of growth might be expected How long would such a person live? How is he or she going to be treated by society? Is the person going to find a couple to live with happily? Will he or she find a job that satisfies? And the most important one: what can I do to help this person?

In this book we have addressed several of those issues based on recent scientific knowledge as well as on direct experiences of authors with children, siblings or grandchildren with Down syndrome. We have taken care of covering the whole lifespan: as human beings evolve so their needs and worries change. We deal with first as last years in life.

There are many questions that could not be answered in the first years of the present century of which many if not wholly answered at least we have good indication on how to. A question leads to several others.

About coping

Would we cope is the crucial point, and the answer is yes. Most of us generally sooner than later first accept and then become totally involved in the child's development. As grandfather (MIG), in my early stages of struggling with the acceptance of my grandson's condition, I heard that some even say that Down syndrome is an essential characteristic of the grandchild and, without it, it would be someone else, and that is absolutely true. It is unconditional love and now I know that it is possible. Those cases where someone cannot cope often hide behind some other problems which would likely occur with or without a baby with Down syndrome (Cunningham 2006).

Accepting is not to deny knowledge so we need to know the general guidelines of a child's development in the first years and how many with Down syndrome take more time to progress through certain stages. Knowing is the best way to give adequate support according to each child's particular needs. There are no simple answers regarding physical or intellectual characteristics and their implications on quality of life, since there is a combination of multiple factors amongst them the environment, including early stimulation, attitudes of parents and relatives as well as the society as a whole, the availability of adequate services in health and education and, of course, genetics.

Recent advances in medicine, psychology and pedagogy have opened up a brighter future; there have been surprising changes and accomplishments not thought possible before. For example, until the middle of last century, Down syndrome was generally seen as synonymous with profound intellectual disability, unable to perform simple tasks without supervision let alone learning to read and write. Independent life was out of the question.

In previous times IQ level, as an indicator of intellectual ability, was considered to range from profound disability to borderline ability and only 3% might be regarded with mild

intellectual disability. By the sixties, this idea began to change, considering that only 20 to 50% had a mild to moderate intellectual impairment with a few individuals even reaching normal intelligence levels. This meant an "increase" of 40 points in the IQ scale (Clunies-Ross, G. 1986). Does this mean something had changed? Of course: our perception of Ds has changed with the opening of a wide range of opportunities previously denied, and better educational programmes, an inclusive life which is every day more common, and there is more research.

Though studies are limited to the small percentage that has access to a full cycle of regular education due to their learning and motor skills, this circle is widening more and more. Inclusive education – where regular students work side by side with Down syndrome children – is becoming more common. Regulatory as well as legal frameworks are in place. It is a matter of enforcing them, in developing and also in developed countries.

What we need in developing countries where infrastructure is weak are more teachers prepared to guide and help children with special needs, having the sensitivity and knowledge to do so. We may even have to modify academic programmes in schools for teachers.

There is still much to be learned about intellectual and cognitive performance in relation to physical handicaps, opportunity and learning methods (Borthwick 1996, Faragher & Clarke, 2014) but advances are encouraging. Development of skills such as reading and writing, considered unattainable not so long ago, constitutes a landmark with unexpected scope in their educational and general development (Troncoso, 2009), although some children with Down syndrome, having other disabilities which sometimes make them bedridden and chronically disabled, might not achieve this, it is a radical change from the pessimistic point of view held not so long ago.

And the big issue, why it happened, has no simple answer: it happened because it is possible, one of many variations in the transmission of information of the complex development plan of a human being. No other reason. Perseverating on this question is useless, what we need to do is to respond to the needs and wishes of the baby, how he or she grows, and how individuality is being expressed.

It is critical to concentrate on the big subject of education, to value him as a person, to make him feel a valued member of the family, showing the pride of having him together with the other grandchildren, for he is part of the team.

Quality of life

This book commences with quality of life, both of the individual and the family, since this is the basis of a happy and full life whatever the conditions.

What is crucial is to encourage the individual to do with his life what he or she wishes, for which parents and families need information to support them: how to do simple things, from taking first steps to acquiring the knowledge of what to do to help the individual have good health and an independent life as much as possible. This requires the development of language and functional skills, to find families with similar experiences with whom to share problems as well as achievements. In short: to be valued and happy. Every child is different and his or her expectations are personal, as in any human being. Having Down syndrome does not mean they all have the same level of skills or handicaps. Assuming that may hinder many opportunities for personal development.

From the perspective of natural sciences it is clear that Down syndrome is just a part of the evolutionary process, a result of Diversity. Life has evolved towards complexity, and this means that variability encompasses within its normality Down syndrome and other "disabilities". Certainly disabilities bring along difficulties in everyday life but most of the time they are not insurmountable, particularly with the help of modern science and technology.

That is why to understand Down syndrome it is necessary to consider all angles: physical, biological, educational, medical and social to make inherent difficulties to be as little restrictive as possible and life may be experience fully. And this is perfectly possible.

As introduction one of the authors MIG narrates his own experience with his grandson Diego; a story as common as many.

I am the grandfather of Diego

Who is Diego?

The most enchanting boy I can imagine; amusing, acute, tender, sometimes obstinate and even a little bit ill tempered – that is as any child of his age. He is prompt to laugh even at himself; he is funny and is aware of that. Has good discipline, learnt both at home and school; takes his turn, queues, obeys when is taken to the doctor and does what he indicates. He is tender with his younger brother, but does not tolerate misbehaviour chiefly in public. When Diego was about four years old they went to the doctor; he was used to that and took it calmly, but not his brother who is quite restless. He screamed when the doctor attempted to examine him, took a lamp he had and threw it away. Diego calmly rose, picked up the lamp, stroked him with it and said, "Don't!"

Ah, incidentally, Diego was born with Down syndrome.

Diego is growing and expanding his spectrum of skills day by day. He does most of the activities his peers without Down syndrome do. One of his few early obstacles was spoken language. But this was not a major handicap; for he was taught along with every child in the Nursery School he attended non-verbal communication such as simplified sign language, which is used together with the spoken word. This open learning environment has helped him a lot; he learned to work side-by-side with children with and without disabilities, and everybody was given the same discipline. One day in the Nursery School he did not want to wear his glasses, so the teacher said, "all right, we will stay here without the break until you put them on" … he did it very soon.

Now he speaks quite clearly actually. When he was young everyone in the family learnt sign language, so it became a common way to express things amongst ourselves and removed for him the frustration of not being able to communicate verbally. By the way, this is quite useful, because instead of shouting from one place of the house to the other "pass me a biscuit" we make the sign. This was the way sailors communicated on sea, for this language has taken its signs from many places, and the same sign easily "translates" at least between English and Spanish, which are the languages Diego manages.

Diego has always liked to speak on the phone, and though when he was young his language was somewhat peculiar he understood perfectly well what was asked and laughed. When speaking on the phone he walks, just as his mother.

Diego is a happy boy and has given happiness to his parents, grandparents, family and friends. When he was young he loved to go to the playground; run from the swings to the slide and then to the see-saw and roundabout. He taught me there to respect his time: when he was finished with one game or not he told me so (sign "finish!" or sign "more!"). Nearby where he lives there is a hill, which he enjoys running down; he is very agile since he was very young. He has swimming lessons and goes with his parents: he enjoys water. He has horse riding lessons, since in England that is important, besides being therapeutic.

Diego understands equally well English and Spanish though naturally he uses more frequently the former. But he does not like that we grandparents speak to him in English. Once he asked his grandmother to read him a book: the book was in English and so she began to read it in that language, but Diego stopped her saying no, no, no: he wished her to read it in Spanish.

The news

When our son telephoned us giving the joyous news of the birth of our first grandson we were crazy with happiness and when a few days later he informed us that he was born with Down syndrome we were devastated. We cried bitterly and did not know what to do; the future was black and blank; what would become of him, to what discriminations would he be subject? What segregated life was destined for him? We always imagine the worst.

Why do such things happen? Why of all children born that day, it had to be my grandson who had what I thought was such a terrible *disease*? Would the doctors be mistaken in their diagnosis?

I had the information any ordinary person has (mostly wrong, actually); basically that those children have a short life, that sometimes they are so weak that have to be fed by a tube, practically helpless, physically and mentally. A baby condemned to a life of segregation and limitations, with little or no

expectations for a good quality of life. I imagined him unable to walk, or do it clumsily, let alone dance or run.

That Friday I had a reunion with my schoolmates, pals from over sixty years. I phoned one of them and amongst sobs I told him to convey my apologies to the rest but I was unwilling to go. I did not want to see or speak to anyone. I did not want to be comforted. I did not want anything. I was angry and scared.

My family respected my feelings and kept prudently apart. Somehow one of them thought to put me in contact with a cousin of mine who could understand my situation well as she herself had a boy with multiple disabilities and since then has run a Centre for children with all conditions. She helped me to start coming to terms with life; little by little she said you will understand reality, sometimes is difficult, but not always. First and above all he is a baby, and what he is going to be he will be revealing himself. Wherever he needs help it has to be provided, the rest leave it to him. It was sensible, but as if she was talking to someone else.

Another thing she did was to give me the names of some people she knew who have devoted their lives to study and help persons with disabilities. They surely would listen to me, she said.

Finally I met my grandson

Then we began the very long trip to the UK, longer than usual; time seemed to extend beyond the normal 10 hours of flight time; it seemed an eternity. Eventually we landed in the familiar London Heathrow which is usually a motive of joy since we lived our years of youth there, but this time it was grey and dull, and not because of the weather, which was a bright sunny cold Autumn day, my favourite time of the year in England. Immigration was expeditious and our luggage came soon; we picked it up and rushed through the nothing-to-declare gate: we needed to see Diego, we needed to see my son and daughter-in-law.

There in the modern hall of Terminal 5, by the dancing fountains, my daughter-in-law was holding a small bundle tightly to her chest. Then she showed us our first grandson, as she lifted the shawl protecting him from the cold: so small, so helpless, and so fragile. We immediately recognised his nose, his chin - so familiar; much like his father many years ago but also with features from his mother. No mistake, he was one of us, one of the family.

He had to be changed. My wife and daughter-in-law went to the baby's changing room while my son asked me how I was and I answered I was fine, happy to be with them, but with a weary smile. A long silence was broken by saying, "What about going to purchase a pack of those yummy doughnuts they sell and we all like?" Conversation ran on the trivialities of the flight, the weather... We eventually came the five of us together and went to the car and away to their home.

The motorway was jammed, and the signs indicated that it was going to be a long delay, so we decided to make a detour and stop at the services to feed Diego. We could also have a proper lunch, since by that time we were really hungry. There we stopped, parked and entered the services, warm, clean and with the look that all services have. We took a seat and finally I could take a long look at my grandson. My grandson, my son's son; a third generation. We had to take him for another change of nappy (amazing how many changes of nappies they require) and now it was my son and grandfather's turns. There we went and with it all of a sudden so many memories of that process I did so many times with my own son so many years ago, in that very country. How tender it was.

After all that, the atmosphere relaxed a little, my daughter-in-law smiled and said this is Diego, my wife held him in her arms and I will never forget the tender look, the pride of holding her grandson which somewhat alleviated the pain. The photograph I took of that instant is one of my favourites, and I carry it with me all the time, in my cell phone. All of a sudden all those bleak thoughts about the future began to vanish: we were together, with my children and my first grandson. We smiled again and we began to think but not to say it, how were we going to confront the situation and how were we going to solve it. The thoughts of *a terrible disease* and *why this thing happens* evaporated. Is it not a fact that you know nothing of the future of your baby, that you help him to construct it?

Arriving home

Eventually we arrived at my children's place. All the agitation of unpacking, giving them our presents and receiving theirs submerged us in a warm reality, all together. I began to take my

first million photographs of Diego: with his parents; his grandmother; with me, with my son, my grandson and myself, all three generations. Eventually the baby seemed to say, "please let me sleep" (or so I understood) and we put him in his cot.

Then I had a moment for myself, alone in my children's lounge that brings so many good memories. Looking at the garden I began to think what exactly is Down syndrome. I saw my baby as very "normal", but what does normal mean? What could I do as granddad? And even though the initial pain began to subside, my ignorance on the subject remained the same.

Holding the baby helped develop a feeling of warmth between us; talking amongst us all helped alleviating our feelings. Once my daughter-in-law told me about a dream she had about her recently deceased father, where he pointed to a baby lying at the roots of a large tree and said, "There is your son". Dreams are symbolic and knowing the amiable person her father was I took it as a message of optimism: was not my grandson to be protected after all by his family tree?

In any case, time heals everything, or so they say, but I still had a number of questions and worries but was hesitant to speak to anyone else outside the family. Then I decided to turn to the persons my cousin had suggested. I tend to be shy with strangers and thus was hesitant to bother them, but I had to overcome that.

I began writing to them. It was not easy, they were busy persons and I was not that sure how they would receive my mails. I found exceptional human beings that helped me to begin walking this new path in my life.

And reality had to be faced. Fortunately health services in the UK are good, and an outstanding paediatrician took care of Diego. Whenever we took him for an appointment he seemed not to have anything else to do except seeing my grandson. Because of that we felt secure. He diagnosed a slight heart murmur and explained that it was normal, and if it did not disappear by itself in the near future he would have to send him for heart surgery, but not until it would be absolutely necessary. And later on he had the surgery and in a very short time he recuperated completely. He is continually checked and what has to be corrected is dealt with.

Meanwhile Diego has been growing. Thanks to present technology we are able to keep close contact and see each other on the computer. He is always happy to see me, we interchange our love … and then he goes to whatever a child of his age has to do; he is always busy.

Every time we are together we do more things and our bond strengthens. He is regularly monitored because his health might be fragile; until now he has been a healthy baby with the usual diseases they catch particularly when attending school. This is important to know because in the past many of these things were not known and might be one reason to believe that children with Ds didn't live that long.

Now I know that Down syndrome is not a disease, that no one needs to feel guilty about it, that it is rather what scientists call a "chromosomal variation" but not that the person has any fault rather it is a consequence of the complexity of life. There is no factual reason why any parent should be "guilty" of producing a child with Down syndrome. It happens statistically in every race and every place on Earth with the same probability. Many pregnancies are terminated when Down syndrome is detected, but I couldn't possibly imagine this world without Diego or any other children with Down syndrome for that matter. It would be like an organism without one of its parts.

Diego is doing fine, other children with Down syndrome are not so fortunate but a lot depends on what we all do. Down syndrome has a vast range of manifestations, from very slight to serious ones. There are some distinctive physical features, since the skeleton and other bodily features are frequently affected but that varies greatly. For some it is quite obvious they have Down syndrome but not all show clear bodily features. The intellectual ability also varies significantly, and has nothing to do with physical appearance.

Many of the preconceived ideas are wrong. When I first imagined Diego it was a picture that had nothing to do with reality. It is said that children with Down syndrome have difficulties in moving because they have a poor muscular tone. Well, that may true for some but I have seen extremely good dancers who have Down syndrome. There are photographers, musicians,

professionals, or actors. If there is something I am convinced of it is that Diego will have his own path in life, and that will be of high quality.

Diego has opened to me a whole new world. Not exempt of sorrow but absolutely filled with human values, which are something to appreciate in a world at times lacking of them.

Down syndrome is a fascinating subject because it involves pure human values. There is indeed discrimination; there is repulse and misunderstanding from some. But there is love; there is the possibility to build new things.

Many things have to be un-learned, I am convinced of that, since they were based on limited facts, prejudices and ignorance.

I shall walk in life proudly with Diego. He is my grandson first and above all. He has a brother who immensely admires him, as the rest of the family do as well.

Sometimes I am confident in the future, some other times I weaken in my confidence. Whatever might happen I am convinced the future is shaped in the present and we shall foresee the gorges to prepare the bridges, as a friend of mine told me once.

I have fears though about a number of things: is he going to be discriminated against? About his intellectual abilities, how severe his limitations will be? If many of these things occur, what professional support can he expect? What sort of programmes or experts are there?

THE ROLE OF GRANDPARENTS

It is never easy to break bad news; there are no specialists, just sensible and insensible persons. In old times messengers conveying bad news were usually killed.

One always considers that situation as a very distant one; "it cannot happen to me" is the common thought. So, after the initial grief you turn to doctors and nurses for answers, but according to recent study (Biasotto et al., 2011) medical students neither receive adequate training to deal with disabilities nor do many of them consider it an important subject. It is not surprising thus that most parents (as cited in the same study) express deep dissatisfaction in the manner the news is conveyed. That study was made for developed countries – Great Britain, Scotland, Ireland, Spain, Sweden, Australia and USA" – lesser-developed

economies have the additional disadvantage of the lacking of information.

Diego 4 years old playing with his grandpa at the Black Country Living Museum, West Midlands, UK.

Grandparents may play a crucial role for their own grandchildren and for others as can be seen from this story: a grandmother lived in a city, and took her granddaughter to early stimulation classes, since the rest of the family had regular jobs. The other grandmother lived outside the city, in an isolated village. She didn't know what Down syndrome was, but began to read and was guided by the grandmother that lived in the city. Now both know "a lot, and when a child is born with Down syndrome they act as advisors and helping hand. They are proud of their granddaughter and like to show how independent she is" This is how things are done in Mexico in the many places where government support is inexistent.

But we should not dwell on rejection and difficulties. There are those who have the capacity to see beyond differences, which may see dignity and equality among everyone, as in the story below, written by Mr Jim Colgan, a friend of one of us (RF) that happened in Canada while on a visit.

"On the last Sunday of August, during the family service at Christ Church Cathedral in Victoria we noticed a young girl with her family about 3 pews ahead of us. On her nose were perched a pair of small glasses. She had two inquiring eyes and a mop of brown hair. She has Down's syndrome. The following Sunday this little lass appeared and sat down beside us. She then proceeded to look through the 'Book of Common Prayer'. Her name is Ruth we found out; she spelt it out for us as we had trouble hearing her small accented voice. She captivated us and the couple behind us. I was reminded of friends in L'Arche* who had taught me many lessons about my disabilities and some lessons in living. Ruth was about to remind me of those things and offer her company and, yes, comfort to us. The Kingdom of Heaven was here and now for me, love and trust, no price tag, freely offered from the most vulnerable and powerless of people. Powerful stuff. All that was necessary was to accept what was offered without reservation and to reciprocate. Ruth is 7, I am 67 and our roles were reversed whether she knew it or not. Here was a small gift from God showing me how to live as fully as one can, vulnerable and powerless and open to enjoy the moment. Deep in my flinty heart I knew the old habits of guarding ones feelings and emotions would take over when she had gone home but still the heart was gladdened and the memory was there and maybe I would be a little better for it."

We hope this book will be useful particularly to parents and grandparents; for they to discover that there is no sickness, or genetic inheritance, or "bad behaviour" behind Down syndrome but just a genetic condition. There are health issues – both physical and mental – to take care which are inherent to this condition; no more. A good summary could be put in a mother's words: "parents, carry on with their child, whatever challenges; grandparents, support him and be present in his development"

---

* L'Arche is an organisation of people with and without intellectual disabilities living in Community. It was founded in 1964 by Jean Vanier, the son of a former Governor-General of Canada. It began when Vanier bought a house and invited two men with intellectual disabilities to move out of an institution and live with him. Within a few years, the idea spread and 50 years later, L'Arche is an international organisation with communities on five continents. The name is taken from Noah's Arc and represents a place of sanctuary. See the website: http://www.larche.org/discover/larche-since-its-creation/

Part One

THE PRACTICE

Ancient Greeks had a word to describe wellbeing and happiness: *eudemonia*, which Aristotle considered to be the supreme good for human beings, not only at one time in their lives but throughout life. In current terms this is the concept of quality of life.

With the development of the social sciences in the first decades of the last century the concept was refined with observations in practice and based on the emerging theoretical frameworks, and throughout the century several ways of measuring well-being and quality of life were developed; see for example the article by Andrews (1974) "social indicators of perceived quality of life".

The concept of quality of life nowadays is the subject of an active investigation, not only in practice but also as a theoretical basis for the development of policies for social welfare. The United Nations considers this to be one of the main topics of interest for persons with disabilities. In chapter 9 this concept is developed further in terms of policy development and application. The aim is to provide a platform or an approach through which specific social and behavioural support and intervention can be developed and provided (Brown, 2017)

In this first part the book focuses on the practice of quality of life, since it is in it that the guidelines have been found to better serve people with Down syndrome and their families, which is the subject of the following two chapters. The quality of life requires a comprehensive vision of the person, in the current moment of his or her life and throughout it; that is why the following chapters deal with friendship, education and how to enjoy life as they age. The first part closes with considerations on health, because for people with Down syndrome more care is needed than for the rest of the population due to the uniqueness of the syndrome.

2
QUALITY OF LIFE AND DOWN SYNDROME

Roy I. Brown

INTRODUCTION

This book is about Down syndrome and the expectations and needs of individuals with Down syndrome and their family members. This particular chapter is concerned with the quality of life of individuals with Down syndrome across the age range and highlights the major features and implications. In many countries the issues of quality of life are being promoted in order to enhance the wellbeing of people with Down syndrome. The level of quality of life varies from country to country and it varies enormously within countries depending on a variety of situations that occur both within families and within the communities in which people live. Unfortunately much of the research on quality of life in the field of intellectual and developmental disabilities concerns mixed groups including people with Down syndrome rather than Down syndrome alone. A few articles based on quality of life have been published on Down syndrome and these are mainly in the adolescent adult range (See for example Adult Down Series, 2004-8; Cunningham and Brown, 2014). What is required now is more research into quality of life and Down syndrome across the age range. Nevertheless the literature on quality of life in the intellectual and developmental disabilities field is highly relevant.

A CHILD WITH DOWN SYNDROME

When a child is born with Down syndrome one of the first things to recognize is the types of services that can be readily made available. These are critical and include the ability of the parents to meet other parents who have children with Down syndrome. It often falls to local associations working with people with Down syndrome and particularly the parents of people with Down syndrome. It is necessary to ensure that new parents know what Down syndrome is about and what may be expected with all the variations kept in mind. This means consultations with medical

personnel, which should include those well informed about recent developments in Down syndrome. A knowledgeable psychologist and social worker should also be included. This may mean further education for health care personnel, as frequently in many countries and particularly in rural areas the availability of such knowledgeable personnel is often limited. Some of the stories told in chapter 2 dramatically illustrate this.

In order to ensure a good start and continuing development an examination of quality of life is important. In this chapter we are talking about quality of life of the person with Down syndrome, and in order to understand this we need to look at what we call domains of quality of life. These include the health of the person with Down syndrome, the education of the person with Down syndrome, the involvement of the child within the family and within the local community recognising these aspects change as the child develops. In other words, it relates to how the child can experience normal social living. At a practical level this includes the friends she or he can make and the types of friends they have. This involves particular aspects of lifestyle including other children they are with when they are very young, the schoolmates they meet and the attitudes of those children and their parents, and also the attitudes of the principals of schools and their classroom teachers, as well as other leaders of education towards children with Down syndrome. This is also true of health personnel including all professionals who see and help the child such as general medical practitioners, social workers, psychologists, speech therapists and others. The fact that many of these personnel do not see children with Down syndrome very often limits appropriate actions which would help to ensure a positive environment and effective intervention.

Other aspects that are important are the economic resources available for the child and the community services that are provided by governments including, and particularly, local authorities. The strength of any community relies to a large degree on the extent to which families are enabled to function in the best possible fashion to the advantage of each of its members, but also for the advantage of the community as a whole.

This chapter is particularly concerned with quality of life across life span. Although many examples are given it should be

recognised that fitting into this approach are a range of teaching strategies such as how to enhance observation by highlighting aspects of the task to be learned, how to breakdown learning into small units, spacing learning into small units of time, and overlearning tasks, for to get it right for the first time is insufficient. These guidelines have been available for many years and are to be found is basic texts and in booklets from many applied agencies, (see the work of Cunningham; Buckley and colleagues; Faragher et al, and Mitchell.)

Quality of Life

The examples relating to quality of life given in this chapter represent the importance of particular principles and the reader, if interested, is referred to other works which describe some of these aspects in more detail (see bibliography below). We shall see what some of the principles are, but first what is quality of life? There are several definitions. These include satisfaction, general wellbeing, not just of health but also of social, educational and other aspects of life, particularly community life. They include obtaining and doing the things that one would like to do. Quality of life is measured through recorded observations, asking questions of the individual and primary carers, rating performance, providing choices and opportunities and with support observing what happens and if necessary trying out further ways to give help and support (see Brown & Brown, 2003; Schalock & Verdugo, 2012).

When we are talking about improving quality of life of the individual we have to ask a number of questions about what this will involve. Obviously it involves issues of basic health (see chapter 8) and the importance of early intervention, and remediation where necessary for conditions which often and particularly apply to children with Down syndrome. There are respiratory issues; issues associated with heart defects or abdominal abnormalities which need to be treated early on and which then enable the child to function more robustly and effectively. When this is done the child is highly likely to enjoy a healthy and more active life.

One of our problems from an historical perspective is that we have separated thinking or cognitive abilities from emotional behaviours and from bodily functions. We have learned over recent

times that a child who, for example, can breathe and sleep properly is likely to be more motivated and engaged in activities and therefore can learn more effectively. A child who has a good circulatory system is likely to be able to sustain activity for longer periods of time and think more clearly. A child who can digest food easily is able to perform thinking in a more appropriate manner and more effectively without major fatigue. Someone who can speak clearly is likely to communicate and relate to people more readily. This leads to the notion that in quality of life there are a number of principles, which are interactive and are important because of the nature of how we function as human beings. The following examines these areas in some detail and it is helpful to remember that physical and thinking and emotional functions are dependent on one another when it comes to learning and performance.

PRINCIPLES AND PRACTICES

Principles and practices on QOL have three main characteristics: (a) have attracted a large number of researchers and frontline professionals, (b) explain or clarify issues that were before confusing or misleading, and (c) open new lines for research and practice. This is the concept of a paradigm as noted by Mittler (2015) with regards to the Convention on the Rights of Persons with Disabilities (United Nations, 2006), which is amply discussed in chapters 5 and 10. Furthermore according to Mittler (2015) QOL indicators can be related to clusters of articles of the Convention for monitoring effects. Later on this chapter the concept is expanded.

The following tables based on the research of Goode 1994; Brown 1997; Brown and Brown, 2003; Schalock et al, 2002 Turnbull and Parmenter in Brown and Faragher, 2014 lists many of the major principles involved in quality of life for the person with Down syndrome and they also apply to family quality of life, which we discuss in detail in a later chapter. Many of the ideas represent actions we should carry out but often overlook or only do some of them. A list like the above gives us a method of checking things out and shows how we can improve life both for the person with Down syndrome and also family life. Very often our students and colleagues say, *"Well, this is what we should all be doing"* and

this underscores another point- people with Down syndrome and their families should live lives that are as normal and effective as possible just like we would hope it could be for everyone. The principles should be applied when very young and onwards. Even if the process is started when the person is older positive impacts are still possible. We have divided the principles into three major but overlapping areas:

(a). General Principles applying to society, community, family and the individual with Down syndrome,

Although these apply to everyone they are particularly the responsibility of organisations that , in consultation with parents and adults with Down syndrome, help to improve societal reaction to people with Down syndrome and help the community to adapt and become very supportive. They also help to develop inclusive processes and explain why they are important.

(a) General Principles applying to Society, Local Community, Family and Individual.	
1. Dignity of disability	Ensuring that people with Down syndrome are regarded as valued persons in their own right, and treated accordingly
2. Ethically based Policy and Practice	Policy and practice based on values relating to society but enriched by research knowledge
3. Personal and Professional Values	Understanding the differences between personal and professional values, particularly critical in delivering services to a multicultural community
4. Duty of Care, Risk and Safety	Risk is a necessary part of learning, but needs to be with support boundaries
5. Normalization	Providing normal life experiences in normal or common environments rather than in excluding situations, or behavioural acts which exclude
6. Exclusion /Inclusion	All aspects of life have opportunities for including or excluding an individual. Only including a parent in conversation means excluding the child

(b) Specific concepts and principles embedded in a QOL approach.

Although these principles are linked to society they are critical in terms of the day-to-day impact on a person_with Down syndrome and Family members.

We will not go through each principle since the implications for some are very clear, (But see Brown & Brown, 2003 for a range of practical and necessary examples). The first 6 principles in the table above need to be taken up by advocates, parent associations, professionals and managers of agencies as well as governments. The concepts should be seriously considered as mission statements for Down syndrome. They should be developed and applied by parent agencies and leaders of agencies and governments in the areas in which they practice including the policies of governments, and agencies (Schalock and Verdugo, 2012). They should also be included in the education of personnel. Progressive agencies should consult with governments encouraging, not just new policies, but requesting these are applied in practice. Many countries have found such developments have huge pay off not least in terms of education, but also family stability and eventually in an increasing numbers of adults with Down syndrome in part time and fulltime employment.

(b) Specific concepts and principles embedded in a QOL approach. Individuals with Down syndrome and Family Members.	
7. Resilience	The ability, due to an interaction of genetics and environment, to deal effectively with challenging situations
8. Life Domains	Areas of life in which we function- e.g. health, community, school, employment etc
9. Holism	Linkage and effects across family domains
10. Lifespan	Individual and/or family development (Integrated services during the person's life)
11. Imaging the future (Forward Planning)	Seeing the possibilities for the individual and by the individual for the future e.g. school is not the end of learning- image and allow for what comes next

There is often the further challenge of remote services in developing countries and particularly in rural and smaller urban areas in most countries, which require urgent consideration of the basic needs of children with disabilities: those essential points on which QOL should start.

(c) Principles that should be applied on a practical level in home, community life and education.

These principles have huge practical impact and need to be applied within the home by parents, grandparent and siblings.

(c) Principles that should be applied on a practical level in home, community life and education	
12. Opportunities and choices	Choices are critical to development and need to be used as much as possible
13. Perception	Perception is a major driver of individual and family members' behaviour
14. Personal Control	Enhances self-image, therefore confidence and knowledge including experience
15. Self-image	Effects of positive or negative self-image, on cognitive and emotional development
16. Empowerment	Providing environments which raise the opportunities for decision-making
17. Inter and Intra Personal Variability	Inter variability refers to the huge variability amongst people with the same diagnosis- e.g. some people with Down syndrome gain university qualifications and have full time employment, whereas others may have very limited performance skills. Intra-variability acknowledges the day-by-day variability shown by any one person, often considerable, with implications for assessment

They are day-to-day activities involving simple techniques, which can be made part of the repertoire of each member of the family*.

* The content of the above tables has been modified from Brown, Roy, I., Cobigo, V & Taylor, W.D. (2015). Quality of life and social inclusion across the lifespan: challenges and recommendations. Special Issue. 'Community care: past, present and future'. International Journal of Developmental Disabilities. (61)2, 93-100 with permission and are further discussed in Brown, Roy. I., Kyrkou, Margaret R., &

It is important to remember that applying any one of these principles will not be sufficient. It seems to be the combination of as many of these practical ideas as possible that works over time. For example, trying to build the self-respect and self- image of people with Down syndrome does not work very well if they do not experience a regular and socially normal environment, which is inclusive, thus encouraging the person to be empowered and make choices.

For example, how does a family consider the dignity of the person with Down syndrome? In what ways is a particular family overlooking exclusive behaviours and situations which occur in the home, and how are they promoting inclusion? Examples include not allowing for an adequate array of choices, not allowing the person with Down syndrome to accompany a sibling who is allowed more access to the community, not permitting choices in clothing and for the older child not supporting the child in having a bank account. Inclusion has become a critical factor in the development of people with Down syndrome, but unless carefully managed can also result in exclusion including family exclusion. At another level has the local parent association held a discussion group on these topics? The challenge is that parents need to become effective in applying these principles and see there is adequate training so parents and other family members can apply the basic ideas.

In the meantime a country needs to expand its range of frontline professionals. This is now happening in a number of countries. What education and training programs are available? They may need to be started through workshops based in parent agencies, but they also should be developed in colleges and universities. In many countries, this is now becoming commonplace.

The notion of *ethical services and support* is important and in the context of abuse and neglect critical issues arise, which need to be reported and action taken when they occur. To simply take care of someone is not sufficient. Support including education, training and experience is critical. In other words there is a need to

Samuel, Preethy. (2016) Family Quality of life. Leslie Rubin, Joav Merrick, Donald E. Greydanus and Dilip R Patel (Eds.). 3rd Edition: Health Care for people with intellectual and developmental disabilities across the lifespan. Dordrecht: Springer.

provide normal experience wherever possible and it is more possible than most people think. So lack of *choices and opportunities* should be regarded as serious concerns and with negative impacts on behaviour.

Many people around the world are not given opportunities to learn. When they are there needs to be protection against serious risks so support and guidance are required and this has to be evaluated through observation and recording so when individuals see progress they feel rewarded, and frequently motivation and self-image are improved. This is called a feedback loop; learning takes place- the person gets feedback over their progress- and this affects their behaviour in such a way that the learning is reinforced and further activities can take place. This is also an example of *holism* as small and larger supports can have multiple effects on overall behaviour.

Most people with Down syndrome can learn how to wash and dress themselves, how to shop, and how to keep track of their money and use a bank with support until they can do it on their own. A few are marrying but need guidance and support- some a lot, some very little. Will they make mistakes and get things wrong? Yes, and making mistakes for all of us is part of learning. It is when error overwhelms a person that the effects are very negative.

People with Down syndrome may be slower to learn than many others, but that should not stop us supporting them- they often show learning in slow motion but frequently master skills. Mastering skills makes them more independent and, for some, enables them to contribute economically as well as socially to family and society.

Experience and education should, wherever possible, take place in regular society with regular opportunities- this is what we mean by *normalization* and at best can represent *inclusion*. This means as far as possible, and its more possible than most people think: being in the same environments as the general population, with the support that they require, but no more. This is a fundamental issue: see chapter 4 on friendship and chapter 5 on education. Unfortunately regular society often excludes, and so we need to educate members of society as to why people with Down syndrome need to be included. A useful exercise is to examine

family life, school experience, and community and employment experience to see how a person with Down syndrome is excluded. It is a good idea to make a list of such items and then do something about them.

Some people think changes in support have to be large but small items of change can generally have cumulative and major impacts on the individual's development. A good example is the following: the author was contacted by an agency manager who said:

" I heard your lecture a number of years ago when you said it is the little things that count in exclusion, so I went back to my service agency and went around making a list of all the things, which could be regarded as exclusion. I then worked with my staff to reduce these negative learning effects."

It is not just agencies in which *exclusion* occurs. It occurs in families, in local communities, in offices, banks, food stores and so on. We need to work with all of these situations and encourage support from colleagues and friends. The positive effects then benefit everyone. Unfortunately exclusion produces negative learning. It is learning- learning how to be excluded, how to be silent, how not to try- that is what an excluding society does to people with Down syndrome. Asking questions such as: - does this person with Down syndrome have opportunities to go to parties with peers of similar age? Is the person learning how to dress and undress, wash with structured support so that with practice they can do it on their own. For older children- can they go shopping with or without a parent, can they make their own bed? And gradually do they have opportunities to use money and then have a bank account- first with supervision then without. If such skills are not being taught then exclusion is building up. The reader may wish to explore other aspects of inclusion. Is the person with Down syndrome meeting other children without Down syndrome, do they go to a playground and meet other children. These are important aspects since this is how they learn and grow up. When they go to see a health professional does the professional look at them and ask them questions or only talk to the child's mother. Does the child experience early intervention in education and go to a preschool programme which is inclusive. Many countries take this much further and include children with Down syndrome in regular

education with teachers and /or teaching aids that are knowledge about learning strategies.

Example: People with Down syndrome from a local group were being taught how to use their bank accounts. The bank manager contacted the agency director and said this was a problem as it slowed everyone down – the bank tellers and the other customers. So a banking program was set up to train the young people and then, it was tried out again with the support of the bank. A few months later the bank manager said to the director: -

"This really worked well, and you would be surprised that our adapted system, with more support from our staff at the bank, also helped the increasing number of older people who use the bank".

Improving things for people with Down syndrome can help other people as well and make an improved society.

This above is just one example. People with Down syndrome in some instances have learned how to drive a car, how to camp, learned to study at university or college, and how to partner and marriage. As one father after learning about quality of life said: -

"I recognized I should leave the door open. I do not know whether my young daughter with Down syndrome will marry, but I must leave the door open to that possibility instead of assuming it will never happen".

In other words it is not a matter of predicting the outcome but allowing opportunities to be explored and permitted, and seeing what develops.

Quality of life is dependent on what we refer to as *domains of living*. These are functions such as health, education, leisure and pleasure activities, economic status of the family, and community conditions and experiences. Each of these interacts with the others, and the resulting effect we call *holism*[*]. In other words one reacts with another and then affects another. It is like a loop with each item affecting the other and interacting in multiple dimensions. For example, appropriate emotional support through mother and/or father affects language positively, and language affects the ability to have friends and who those friends might be. Better circulation (i.e., better health) means more energy and more energy means you

[*] This is a concept meaning that the whole is more effective than the sum of the parts on their own

can learn more effectively. Another important area is involvement in leisure activities, which sometimes in later life become employment activities. People with Down syndrome often enjoy the fine arts – drama, painting, drawing, sculpture and pottery. It is important that we provide at least opportunity, encouragement and support in all these areas, and sometimes we can solve problems or challenges by using strategies, which seem rather remote from the basic condition or situation. For example, having fun and lots of play can affect physical health. So it is very important that we provide an environment in which play and enjoyment are readily available. Going to an inclusive drama class can help the person with Down syndrome to develop in many ways such as language, motor skills, social behaviour, attention, personal control, along with developing a network of friends. Of course, if this happens the person with Down syndrome will want to try many other activities and this should be encouraged with support and guidance. All of this does not happen without trial and error. Parents sometimes want to get a move on when their child is slow carrying out an activity such as putting on their shoes. Time needs to be provided for learning such skills.

However, it is critical to know what interests the person, and that is where to start because that is where they are likely to improve most, and that affects self-image and motivation and then they begin to try other activities. That is why Special Olympics are so important.* With greater self-confidence they are likely to achieve more. This is one of the reasons why the Special Olympics are so important. Think of the many ways individuals can increase and improve attitude and other aspects of behaviour. The effects on the family are also very considerable, increasing the overall level of family quality of life.

Another principle of quality of life is *self-image,* which is how individuals think about themselves: creating a positive rather than a negative self-image. So a child, who thinks that because they have Down syndrome and believes they are not like other people, can be disadvantaged in terms of their self-image, and how

* This movement was founded by Eunice Kennedy Shriver who had a sister with intellectual disability. On July 19 and 20, 1968 the first Special Olympic Games were celebrated in Chicago, Ill, USA, and from then many events are celebrated all year round. The website for special Olympics is http://www.specialolympics.org/

they perform is harmed unless positive input occurs. Some, when positive self-image occurs, come to view having Down syndrome as a positive aspect of their lives (see for example Natalia's story-chapter 11). What is important is creating environments in which the individual is given every opportunity to learn and is encouraged to do so and given the supports that enable the child or adult to see themselves developing. Enabling successful people with Down syndrome to speak with groups of other people with Down syndrome is important, for the former when carefully chosen can act as peers, good models, and be effective advocates. That is why chapter 11 was written.

Empowerment is another important principle providing opportunities to try things out even though there might be risk involved. Some parents believe children with Down syndrome should not take risks. The trouble is that a person who has not learned how to deal with risks, with support, is going to be much more vulnerable than people who have taken risks and with support have managed to learn how to look after themselves. So there is a nice judgment between risk-taking and support to do activities, which may be rather more challenging.

Another important principle is *variability*. Children with Down syndrome are highly variable in behaviour and possibly show a wider range of variation than the rest of the general population. For example their intelligence level varies from very low to average and occasionally above. There is some evidence suggesting that the Down population around the world is gradually improving, that is they are improving in functioning level, probably because of the medical, educational and social improvements that have been made, and that includes the positive changes that have taken place in many families with acceptance and support of their child with Down syndrome (see Borthwick, 1996). Cognitive ability or intelligence is an interaction of genetics and environment and at this point it is the environment which is critically changing allowing for increasing development. This means the child with Down syndrome obtains a higher quality of life than previously and that overall their families do as well. In other words investing in children with Down syndrome is a humane venture, and an economic one and a stabilising one for the family.

People with Down syndrome also show variation in behaviour over each day. Although that is true for all of us there are some reasons to expect it would be more the case in people with Down syndrome. Fatigue may occur more frequently due to health issues including vascular challenges. Some have multiple disabilities such as motor difficulties and others have thyroid deficiencies, which are still not being diagnosed as well as they should be. Indeed appropriate health intervention is absolutely necessary and improvements can be made.

Social activities play an important role as children grow and develop and increase in sophistication from playing simple games, to joining sporting clubs and carrying out social activities, such as clubs, scouts, and guides. Many now use the Internet where friends can be made not only with other people with Down syndrome and, for some, international friendships resulting from trips abroad (Brown, 2009). Cycling is a popular activity for some and a few have learned to drive a car. The last named may seem unusual and indeed it is not common. One of us (RB) has been involved in the training of people with Down syndrome who have learned to drive a car, and drive very safely over a long period of their life. That does not mean everybody with Down syndrome will do this, perhaps only a few at present, but it does mean it is possible for some.

One young man with Down syndrome worked in a gas station pumping gas. He also learned to drive a car and passed his driving test. He went for long drives in order to fish in lakes in the hills. He also began to look after his aging mother.

Such successes are still quite uncommon, but is does illustrate that Down syndrome itself does not necessarily prevent a wide range of learned activities; it is the societal stereotyped view of Down syndrome which gives rise to lack of opportunity and then in many instances failure to learn. The above section on social behaviours is often called social intelligence. Many people with effective social intelligence can do well in the community, and in some employment, suggesting that just looking at Intelligence or IQ is not an effective predictor of performance in the future.

One of the important things to really understand is the dramatic change that is taking place for people with Down syndrome in terms of *lifespan*. In 1900 in Europe it was likely that

a child with Down syndrome would live for about 11 years. There would be variation around this, but that was the average life expectancy. Today it is about 55 years with one in ten living to the age of 70, and life span continues to increase, therefore is becoming much more similar to that of the normal lifespan in a developed country. This raises important questions, because when your life expectancy is not that great then people are disinclined to invest a lot in that individual. Although it is sad that most people with Down syndrome died young, people did not expect there to be a payoff in terms of care, education and community living. But the point, because today people with Down syndrome are living much longer due to better health and education, is that it is important to provide the best of services. Otherwise we are going to find that society has to take care of individuals totally, rather than put them in a position where they can function in a wide range of activities and be part of the regular community. This is not only an important aspect of civilization and our care for children, but also represents an economic issue for the child, parents and their families, and wider society. In other words society needs to adjust to a large degree to ensure that such children can learn and function and take care of themselves to the highest degree possible. No doubt we will find this is very variable, as indeed is now being shown in developed countries, but it is important that such children should be provided with the best of services. Interestingly enough as we develop these services we find that they are relevant to a wide range of other children because they represent the best practices in relation to health, education and community living.

Lifespan as a principle is important for other reasons. It means that parents need to consider the future for their children. Experience suggests parents can be so concerned about the present that they cannot consider aspects of the future. Not only is it important to learn about what effective schools and schooling are available in one's area, but also contacts need to be made with other parents and find out their experience. Parents need to consider availability of employment, and so do school systems. It is no good finding that, although there is effective education up to 18 years or thereabouts, there are very few suitable jobs available. This is a major challenge in many countries but a recent study in Rome, Italy shows that if there are few employment possibilities

available the skills of adults with Down syndrome start to diminish (Bertoli et al, 2011). Parents become more stressed and individual people with Down syndrome start to attend agency workshops, which are not an inclusive employment practice, and self-image often diminishes.

There is another aspect of *lifespan* for the person with Down syndrome and that is ability to *image the future*. This means considering what might happen later in life. What does the person with Down syndrome want to do? Nurturing employment, even if it turns out to be part time, is critical. Watch for signs that the individual wants to have a life like other people and promote it. But this means helping to create an environment where this can happen.

How does a child or adult with Down syndrome think? Do they think in picture images, in sounds and language images, in bodily sensation and so on? A few people, whether those with Down syndrome or not, do not report visual or other kinds of imagery. Indeed they may not know what you are talking about. In our experience most people we know with Down syndrome think in picture and visual motion, smell and so on. Sometimes their imagery is very active. We believe such imagery may be encouraged and developed, as indicated earlier, by joining drama and other fine art classes. RB's daughter, Elizabeth, is an actor who teaches drama to children. She indicates that children often do not learn their lines very quickly. But recently she said I have one child who learnt her lines very quickly. Remember this is a group of children who generally have no obvious disabilities- they just like drama. My daughter said "Oh, it a young girl who has Down syndrome". She had also already acted in a film. Imagery is an important attribute and can be a resource people with Down syndrome can draw upon with encouragement. See for example an illustrative story in chapter 6.

There is little doubt that many people with Down syndrome can achieve far beyond what has been thought in the past. For example, today we are beginning to see people with Down syndrome marry. And there are some very good reasons why this can be supportive to their overall life. One of us (RB) interviewed people with Down syndrome who had married (Brown, 1996). One couple had a support group. RB asked how they are the same or

different from other married couples. The reply was they are the same but happy more of the time! Of course marriage does not work all the time but that is true in society as a whole. How many people with Down syndrome marry? We do not know but practical experience with families suggests it is happening more often than it used to and, to the surprise of the families, it tends to work well particularly with support.

Parents need to recognise that people with Down syndrome have sexual feeling like the rest of the general population and practical understanding of sexuality and its implications are important and should be taught in a positive fashion. Many Down syndrome societies around the world have education content for this purpose (for example: Down syndrome New South Wales Library Collection). Some parents ask if a marriage can result in children with Down syndrome. Fertility seems to be much reduced in people in Down syndrome most likely due to genetic incompatibility. Bovicelli et al (1982) in an early article collating data on pregnancy and Down syndrome indicated only one male with Down syndrome has been known to father a child, though there are more recent examples of this occasionally occurring. In women, fertility is much reduced. When pregnancy does occur frequency of Down syndrome amongst the offspring appears around 1:3, though recent information suggests this may be higher (see Sheets, Crissman et al, 2011). The majority of those people who are married that RIB has interviewed indicate they want to make sure they do not have children but there are certainly exceptions. So marriage and partnership are possibilities for those who fall in love, and are socially responsible, reasonably capable, and able with some support to carry out an effective relationship.

Some positive reasons for marrying-

- Having someone special to love.
- Sharing tasks around the home.
- Being more included because between the two people more friends are around.
- Getting more exercise.
- Feeling more like other people.

There are many adults with Down syndrome, but far too few of them have regular jobs. We are seeing more and more people with Down syndrome in society, and increasingly, opportunities for open employment have emerged. Employment ranges from simple tasks, like collecting trolleys in supermarkets, delivering items, as well as working in motels and hotels to carrying out quite sophisticated activities because they have vocational qualifications (see chapter 7 on education). For example, recent innovations in the Holiday Inn chain of hotels in Singapore have spread across the Asia Pacific region. Managers of hotels find employing people with disabilities, including Down syndrome, has economic benefits such as stability of workforce, and training benefits (well trained employees stay with the firm for many years saving the company money in the long run).

In Mexico there have been interesting examples*, such as the one of a young lady with Down syndrome who has been working for 8 years in the call centre of a bank, Banamex – part of Citigroup – and has opened the way to a group of colleagues also with intellectual disability who have now joined the Bank. Her performance has been so good that the Director for Human Resources has publicly expressed his satisfaction and has set her as an example to her co-workers, for her promptness and quality of work. Something similar has happened with her ex-boyfriend* who was promoted for his excellent quality of work. And this is not limited to one organisation; other companies have had equal success stories. Microsoft hired a receptionist who not only does a splendid job but also has led to a labour climate which is cheerful and positive. BBVA Bancomer, another bank, developed a programme of labour inclusion with 11 persons with disability with such a success that the group is considering extending it to other countries. SAP, a German company developing software for enterprises and large databases has hired 10 persons with autism for its technical areas with such good results that have decided to

* This information was kindly provided by Fundación Inclúyeme whose mission is to be a catalyst to improve the life of people with disabilities in Mexico. There are many more examples in their webpage http://www.incluyeme.org/

* It is of interest of mentioning having an ex-boyfriend is a normal process among young women

globalise the project and its next step is to do it in Brazil and later on in Mexico. More examples may be given: MetLife, IBM and other large companies have hired persons with disabilities for data capture, receptionists and assistants, to cite some.

So what jobs seem to work out well? It is only the beginning, and we must work on this aspect. The Labour market has been opened and other areas should be explored, such as establishing their own businesses, acting in television, films and theatre; hotels and restaurants, support jobs for businesses and government offices. Recently in the city of Cartagena, Colombia, the tourist guide was a very lively person with Down syndrome. There is often a special talent in the arts, as well as crafts, in which with encouragement and the development of their skills they may reach high standards.

Here are some further examples:

- Having, with support, one's own business, artistic painting, making Christmas and birthday cards and other fine art activities. (See Dylan's story on chapter 11)
- Acting in television, live theatre and films.
- Cleaning in hotels and motels.
- Office work. (See Natalia's story on chapter 11)
- Work in childcare centres.
- Helping in a super market or store.
- Working in a restaurant.
- Carrying out public duties and helping visitors in various establishments such as government offices, shopping centres, agencies of many types. (Remember the story of the tourist guide told above)
- Crafts, such as carpentry, electricity, pottery, jewellery,
- There are many advantages which can result from such work:
- Better overall quality of life, improved physical fitness; more friendships are made amongst the general population.
- Earning money, giving a boost to self-image and increasing empowerment.
- Improved language and motor behaviour.
- Improved social behaviour.

A few very able people with Down syndrome now attend college and university and there have been some very positive results. A few are already getting diplomas and certificates.

Equally, or more important, others that attend start to develop more widely based friendships as they are given peer tutoring by other students who help them to understand and learn. What a good way to broaden inclusion. It has certainly pleased the parents of these young adults (See Hughson & Uditsky, 2007 for further information). There is some evidence that many adolescents and adults with Down syndrome know what they would like to do. Parents often know what the skill challenges are for their son or daughter (Grantley, Brown & Thornley, 2001). The skill is to meet the choice of the former while filling in practical gaps in knowledge recognized by the latter. This is often aided by skilled counselling and by practical opportunities to try things out.

The above seems to indicate that society is changing its perception towards a new culture of successful inclusion both in formal enterprises and in other activities. This may enable them to express best their own skills and competences. This is a way recognise the individual skills rather than disabilities.

QUALITY OF LIFE AS A PARADIGM OR MODEL

Quality of Life is increasingly seen as a paradigm (Brown, 2017), and it represents values and attitudes and general principles (such as positive self-image) into which other supports and interventions can be placed. For example, using the principles as part of a paradigm indicates that it should be the structure into which any education or training, including daily life in the family are developed. It then provides a productive environment in which effective learning strategies can take place. Many learning supports have been known for a long time but are still not regularly understood or applied at the frontline level including by parents in the home and their local community. There follow a brief presentation of some of the more relevant and practical ways that can assist in learning.

1. Familiarity and unfamiliarity. Learning takes place more effectively in familiar environments. Unfamiliar environments reduce the ability to both perform and learn. For example people with Down syndrome and those with other disabilities reduce the amount of words they can use and also reduce their motor responses. This is probably a major reason why people with Down syndrome shut down some of their behaviours

when they are taken to clinics and offices which they do not know. (Brown & Hughson, 1993). So before starting on behavioural assessment or learning a new task ensure the person is familiar with their environment before starting the learning.

2. When tasks are too difficult people start to use language which is redundant in terms of learning a task. This also occurs when they are familiar with the tasks. The real problem is encountered when a task is too difficult, which indicates the individual is no longer paying attention to the required activity. So in learning something new we need to check the individual does not have a task that is too complex, as we need the child to both understand and use language that is relevant to the activity. As an aside it is not uncommon for people with Down syndrome to talk aloud when it does not seem necessary this 'Self Talk' often worries parents as they see it as a sign of abnormality. Generally it is an attempt to structure the situation they are in and a normal process which most of us do sometimes. It also occurs in older age as an elderly person attempts to control what they are doing. .
3. Both 1and 2 are associated with stress. Greatly increased stress levels are not helpful in most learning environments. Remember what is not stressful to you may be stressful for a person with Down syndrome. That is why it is important to gradually deal with the unfamiliar in terms of gaining experience about it- like an unfamiliar shopping centre, or a new school or going to the dentist and learning a new task.
4. Remember behaviour goes from the gross to specific. Think of a child learning to walk or hold a spoon. To begin with they use many more muscles than when they have mastered the task. That is why in the former they tire easily, get irritable and sometimes cry and perhaps fall asleep during the day.
5. In the above and other contexts it should be understood that unfamiliarity promotes variability in performance and causes cycling of behaviour.
6. There are methods or approaches that can be used to overcome some of these difficulties. We have already mentioned making environment and task familiar. That is why Quality of Life underlines the use of choice. If someone chooses an activity or

a new experience it suggests they think they can cope with it and therefore choice often promotes effective learning and behaviour.

7. Are there other ways we can promote learning? We can make learning more effective by breaking tasks down into smaller portions- how small depends on the observed basic level of the person's behaviour. This also applies to how long a task is presented. In some cases where there are severe difficulties it may be for only a few seconds. We can also colour code items when we want a child to pay attention and respond appropriately, or sometimes make larger the item we want them to attend to and smaller the one we want them to ignore as in learning to read words. It is important to remember when a person stays too long on a task they become stressed and fatigued. So what are they learning? They are learning to fail. They are learning how not to concentrate or attend to the task in hand. In fact RB has witnessed teachers saying the child cannot learn when in fact the child is learning all sorts of things we don't want them to as illustrated above.
8. In early stages of learning people with Down syndrome do not quickly recognize what they are supposed to respond to which slows their learning. Once they know and understand what they are to do they frequently learn as fast as other people. So once again enhancing cues can shorten this first stage of learning.
9. Auditory, visual and tactile modalities are all critical to effective learning and appropriate behaviour. Although as a rule people with Down syndrome have difficulty using language compared with people without Down syndrome, they understand very much more than most of us think they do. One of the challenges is that both spoken language and comprehension of language diminish in new situations and particularly when learning new or difficult tasks. It should also be noted that people with Down syndrome comprehend more words and sentences than they can speak. That is true of all of us but the discrepancy is much greater than in people without Down syndrome. What teaching implications does this have? They seem to pick up visual cues rather than auditory information when they have difficulties so pointing to an item or demonstrating an activity is often going to have more effect in

such situations. Further, at times they can regress to tactile behaviour, perhaps more readily than the rest of us, so it can help to touch and gently guide their hands in teaching a motor visual or allied task. These same cueing techniques are also useful tools as people age.

10. In all the above, try to reduce negative responses to the person with Down syndrome and wherever possible provide auditory, visual and tactile reinforcement. Find out what a particular person responds to best. Even if the child makes no or little progress find ways of giving positive remarks. E.g., You are trying hard today. You will soon get it. Or if trying hard a touch of the hand and the statement "good try" can be very rewarding.

AGEING AND DOWN SYNDROME

One final aspect not yet discussed is aging and quality of life amongst people with Down syndrome. The average life span of people with Down syndrome in western countries is approaching 60 years and 1 in 10 live to 70 years. Many individuals with Down syndrome face a number of challenges particularly noticeable and appearing during their mid forties and fifties. Dementia including Alzheimer's disease has a higher frequency amongst people with Down syndrome than the general population. The diagnosis is rather difficult as its early onset is hard to distinguish from depression, which increasingly is being noticed in adults with Down syndrome. Tests are being developed to help sort out this differential diagnosis but treatment remains a challenge.

Practical advice includes: -

1. Ensure early milestones and experiences are as normal as possible,
2. We must solve the social activity and employment challenges for these adults. The lack of employment and a typical social life is often associated with deterioration, and this is likely to be at least partly the result of exclusion and low stimulation. The impact of increased lifespan is likely to have profound impact on individuals and their families. It is everyone's interest to see this increases in longevity result in high QOL both for the individual and family members that is why we are stressing a positive lifespan approach.

3. As people age it is important that families work with their relative with Down syndrome to ensure he or she will have accommodation which ensures their wellbeing, experience effective professional advice and support regarding aging, and have a consistently active leisure time in retirement as possible based on their wishes and interests. That may include still living in the family or extended family home and where appropriate, because the other family situations are not available, accommodation in small group homes within a familiar and suitable community (Jokinen, Janicki et al, 2012; 2013).

SOME MAJOR AND DIRECT QUALITY OF LIFE SUPPORT ACTIVITIES

The individual with Down syndrome should as far as possible experience normal social living, and it is more possible than most people think.

It is important to apply principles of quality of life remembering they are interactive and there is more than one-way to solve a challenging situation. Those involved in support need to be problem solvers.

One should use a combination of principles for best effect in development, (See Table 1).

- Remember that people with Down syndrome are highly variable in performance and learning.
- Ensure leisure, sport and fine arts are available to the person with Down syndrome and, where possible, within a community context.
- Use inclusive practices and identify and remove or reduce exclusive practices at home, in community, school and in employment.
- Provide a range of environmental experiences so that ideas and interests can develop and be maintained.
- Provide choices and then try to make their choice a reality with support.
- Help the individual to think positively about themselves, providing examples of success and further opportunities to try things out.

- Ensure there are opportunities to build friendships, face to face or though the Internet with other people with Down syndrome or other potential friends.
- More employment options with support need to be made available for people with Down syndrome if adult quality of life is to be improved.

SOME MAJOR GROUP RECOMMENDATIONS BASED ON QUALITY OF LIFE PRINCIPLES

All those involved with Down syndrome need to help develop policy statements at all levels of practice using a bottom up approach from parents and people with Down syndrome to government levels for co-ordinated and agreed implementation (see chapter 5).

- The individuals with Down syndrome needs to be linked into Down syndrome associations along with parents for information, options and support, and give them opportunities to sit on committees and boards.
- Encourage and involve professionals with effective knowledge of Down syndrome to work with parent organisations in a practical way and also directly with individuals with Down syndrome.
- Encourage and co-operate in the development of educational programmes in universities, colleges, schools and parent associations for students and those already in the workforce.
- Encourage Research into Quality of life and Down syndrome across the age range.

3

FAMILY QUALITY OF LIFE- CHALLENGES AND ISSUES

Roy I. Brown

To be truly radical is to make hope possible rather than despair.
RAYMOND WILLIAMS, Welsh Poet, 1921-1985

INTRODUCTION

Families who have a child with Down syndrome represent a noticeable group within any country. Until recently detail studies have been undertaken to assess how a child with Down syndrome affects the family quality of life.

Families who have a child with Down syndrome represent a noticeable group within any country. It is estimated that in Mexico 1 in 800 live births have Down syndrome that is 0.125% of the total live births. For a population of 130 millions the figure is close to 156,000.

The incidence rate of Down syndrome may be changing in countries partly associated with women having babies later in life, though the figures may need further adjustment because of an increased abortion rate.

Down syndrome is the most common of the chromosomal abnormalities in the field of intellectual and developmental disabilities, and is highly variable. The challenges that face such families, although highly variable, are represented in all countries though the levels of wellbeing and satisfaction are often very different. It is not just the chromosomal abnormality and gene arrangement that are associated with variation, but also the environment in which the individuals live, making a complex mosaic which argues not only for individualised treatment of the person with Down syndrome, but also the types of support and understanding required for family members.

It is very important to bare this in mind because, as we have seen, at one level there are children with very severe challenges, sometimes multiple challenges, because Down syndrome on

occasion is combined with other genetic or environmental conditions. These represent the most challenging situations for families.

There are other families where the effects of Down syndrome are very mild and we find that those children often grow up to live lives within the community doing many of the things, if not most of the things, that other people do. That is they obtain jobs, they on occasion obtain qualifications from universities, and in a number of cases gain certificates and diplomas and work in the areas in which they qualify. However these do not represent the majority. The majority have rather more severe disabilities but nevertheless are able to increasingly function effectively in a variety of ways.

The ways parents and other family members react to having a child with Down syndrome also varies. For many, they find the first supportive contact is another informed parent with a child with Down syndrome who has been through the birth and early years of development of their own child. Health personnel including doctors do no always know how to support parents appropriately though they may be excellent over physical support and early intervention. The availability of a suitable parent in the first days after birth is often a necessary and appreciated support. Not surprisingly families who have a newborn with Down syndrome find that there are changes to the values which they hold about family, health, education, employment and community life. Fortunately many families resolve the new situation by becoming much more interested in spending time with their family members and doing things which enhance family life. A noticeable number of families not only find considerable satisfaction in what they do but also often tell us that having a child with Down syndrome has enhanced their quality of life.

> As a father of our youngest child who happens to have Down syndrome I believed it important to give more time to family life rather than work for promotion. This has led to many positive changes. We have marvellous vacations. We are not caught up in the 'rush' of life. My wife and I share caring for the youngest child in the family and her siblings are supportive and include her in family activities. Life is very rewarding."

However, it would be true to say for the majority of families, where there is a child with Down syndrome, very specific challenges frequently arise which can impact all the members' quality of life. Many of these challenges can be dealt with, with understanding, counselling and support. At present that support comes in many forms, primarily for the child with Down syndrome, but also, and increasingly in some countries for family members who at each stage of their child's development face new challenges, whether that involves the local community, other family members, school systems, or community at large. To a considerable degree, lack of appropriate support occurs mainly because the general population still does not understand the changes that are taking place in relation to Down syndrome. These changes demonstrate, if children with Down syndrome are to have optimal development, support for the family is often a necessary requirement from individuals and services outside the family. Some families are very resilient, but others are not, or they have periods when it is difficult to cope with the result that family support is urgently needed.

It was not so long ago that in many economic developed countries children with Down syndrome were sent to live in institutions or in some type of residential facility, or they were kept at home, as in countries like Mexico. It was also true that many of them received only the basics of education if at all. Perhaps even more critical, at least in the early years of their life, medical and other health interventions for serious problems were not readily available. So in today's world where there is the development of a wide range of professional support services, opportunities are very different from even a few years ago. Intervention in terms of dealing with medical challenges such as heart conditions, challenges in terms of the digestive system, and the issues associated with respiration and allied conditions can now frequently be dealt with early on.

There are still some people who do not think this is worth doing. But the evidence is contrary to this and illustrates the way changes in terms of health intervention have really changed people's lives with Down syndrome. Not least because physically they can function more readily, they have more energy and physical limitations are to a considerable degree, minimized. This

then is an important factor in relation to family health not just the child with a disability.

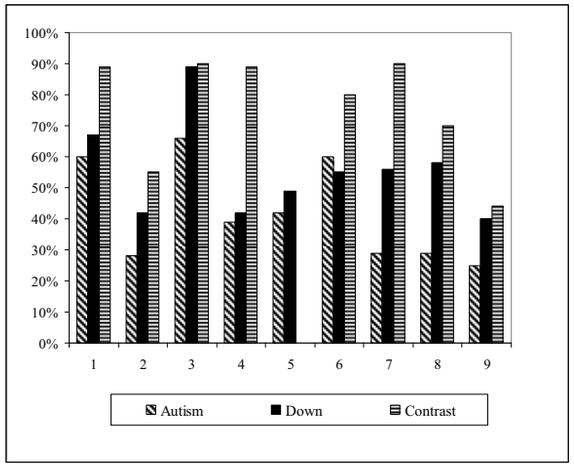
QUALITY OF LIFE IN THE FAMILY

In the field of family quality of life there are a variety of challenges which require understanding and support. Briefly, in terms of research studies on family quality of life, it has been shown that for many families with a child with Down syndrome, family quality of life can be of a very high standard and particularly in specific domains. For example, it would appear that for many people with Down syndrome family quality of life for each member of the family is as a rule reasonably high; though not as high on average as families where there is no disability (see Figure 1). It is considerably higher on average than in other families who have children with major behavioural and emotional challenges (e.g., autism). Although financial issues can be a challenge many families with children with Down syndrome are satisfied with their financial status. Finances however, become more of a challenge when there are other complicating factors such as major physical illness or emotional disturbance. The issues of family finances also become more critical in economically poorer countries and also where up-to-date government or government-supported services are limited or parents are charged a fee (See Brown et al 2010, for further details). A large majority of families put family quality of life and family relations at the top of the list and, as can be seen in Figure 1, in Down syndrome this average closely matches those families without a child with a disability. The data provided in Figure 1 is for young families. Data from research with mixed disabilities across the age range suggest similar responses in terms of domains, though further research is required.

The following graph shows the percentage of those families indicating they are satisfied or very satisfied with their quality of life in the domains indicated for 3 groups- a) where there is a child with no disabilities, b) a child with Down syndrome and c) a child with autism, (for further details see Brown, R. I. et al. (2006)*.

* Based on Figure 1 page 240 from the following article Brown, R. I, MacAdam-Crisp, J., Wang, M et al (2006) Family quality of life when there is a child with a developmental disability, Journal of Policy and Practice in Intellectual Disabilities, 3,(4), 238-246 with kind permission of the Editor.

Data percentage of respondents satisfied or very satisfied with Family Quality of Life for each domain



Domains

1. Health
2. Financial Well-Being
3. Family Relations
4. Support From Other People
5. Support From Disability Related Services
6. Spiritual and Cultural Beliefs
7. Career and Preparation for Career
8. Leisure and Enjoyment of Life
9. Community and Civil Involvement

Autism (n=18); mean age 7.78 years; range 6-13 years
Down (n=33); mean age 7.55 years; range 2-12 years
Contrast (n=18); mean age 6.81 years; range 4-12 years

Figure 1. Comparison of three groups in relation to family quality of life domains The domains are in the order used in the Family Quality of Life Survey

We have to make major changes in our perceptions of and our understanding of Down syndrome so concerns can be addressed. By this we include members of the local community and the officials running community and government social services. Many parents indicate, when they have young children with Down syndrome, people in the local community often ignore them. This may come about for several reasons: - 1) because members of the community do not know how to react when they see a family who has a child with Down Syndrome, but also, 2) because parents of children with Down syndrome are often very sensitive to how others may feel. There is also a tendency amongst older children and adults with Down syndrome, though less than previously, for some parents to dress and treat their child as if he or she is still a child regardless of age. In these circumstances the parents do not follow the morays of children of different ages, but

maintain them in a childhood state. This does not help the growth of the person with Down syndrome or the growth of the family. For example, how a child dresses and the clothes they wear should be very similar to how children of similar age would dress. Teenage and adult offspring should dress as adults and be involved and, if interested in doing so, choose their own clothes. Their interests are likely to be fairly similar to their non-Down syndrome peer group as illustrated by Denholm (1991). Further, their interest in music and social activities is likely to be that of children of a similar age. When this is permitted to develop naturally it helps not only the youngster but also makes family life more normalized and siblings in particular frequently encourage such normality and the local community is more likely to view them as inclusively.

The primary carer (generally mother) in the vast majority of cases says she has much more time involved with caring than she would like. It is also as a rule much harder to raise a child with Down syndrome if there is a single parent family. For some families the severity of the condition of Down syndrome, particularly where there are no or inadequate early intervention services (health and education) can be a further challenge. As indicated earlier, there are also greater challenges when Down syndrome occurs in families where there are other disruptive patterns or conditions present (e.g., autism). It is also more difficult if grandparents and other relatives do not understand what is happening and why certain supports and interventions are necessary. In general terms the outcome is much better than most people expect and tends to be best when there is a supportive extended family provided that the approaches taken are consistent. Sometimes that does not occur.

Because of a tendency to obesity Raoul 's mother provided meals which were suitable and appropriate for him in terms of age and weight. But twice a week grandma looked after Raoul and she gave him whatever he wanted to eat. Some of those foods were not helpful for Raoul's food regime. When alerted to this issue Grandma said- "He is not that big and anyway Grandma's should spoil their grandchildren so I will always give him what he wants and I am his Grandma"

Occasional treats are in order, but this type of situation can be disruptive in training and have negative effects across the

nuclear family. Yes, choice should be provided but it must be done in an overall pattern of structure. Such concerns arise fairly frequently.

Development is also improved when there are lifespan services available. Unfortunately this is not necessarily the case and policy development is different and crosses several government departments. Where there are more severe challenges then greater stresses go on the family, with the result that if there are not resources in the community to provide the necessary support, further stress and disruption takes place. A parent, or parents, may have to give up employment to look after their child with Down syndrome (see figure 1). Or they may have to take a job, which limits financial remuneration and puts a strain on all the family. It is important in society that we take these things into account and enable those family members to have opportunities to adjust their lifestyle to help them do things that accent and support family values. This may be having part-time work rather than full-time work. It may be enabling parents to go on studying as adults to obtain better qualifications so that improved employment possibilities are available.

All this means changes within society and local communities. This includes the need for parents to get adequate personal time and share personal time as well as having time, for example, to meet spiritual needs. Here religious organisations can help by providing a welcome for children with Down syndrome, allowing them to partake in services at the appropriate age and providing respite so parents can attend religious services if they are so inclined. It is important that they can take their child to their place of worship, and the child, where able, is empowered to take part in the services and acts of worship as is increasingly occurring (Crompton and Jackson, 2003).

If life gets more challenging, so the stresses become greater and once family members, particularly mothers, become under stress, then there tends to be tensions within family structure and makeup. It is in all our interests that these difficulties should be minimized and therefore we have to organize supports in our community so things can be readily dealt with.

In some families there are unusual emotional difficulties associated with Down syndrome, though that is not normally the

case, or there are additional conditions, such as Prader Willi syndrome* or autism, both of which occasionally occur with Down syndrome. Early diagnosis and appropriate support and treatment are necessary. Many countries around the world have effective diagnosis and tend to be increasingly positive about intervention in relation to physical health but have not always recognized the importance and kind of support needed to enable families to function with the highest possible quality of life (see Brown & Brown, 2014). That means changes to our education system, and changing aspects of our health and social services.

It is difficult and stressful for example, when parents cannot get speech therapy for a child with Down syndrome, which is often necessary. It is stressful to family relationships and harms all family members if an individual cannot obtain early intervention which is one of the most important aspects of education and socialization enabling the child with Down syndrome to keep up with, or more nearly keep up with, their age peers. In other words, the more behind a child becomes, the more difficult it becomes to catch up and the more family stress is likely to increase. So early enrichment and support are extremely important. But we think of them as important for the individual whereas, in addition, they are important for each family member, because seeing improvement, and seeing development makes considerable change in the family members' quality of life. For example sign or other augmented language is important for some children and adults with Down syndrome, but it is also important for the family as well because communication is enhanced.

Another example is the increasing recognition of depression amongst adults with Down syndrome. Both genetic and environmental causes probably interact here. While we have noted the importance of normalized life style for adults with Down syndrome we should also remember that without such developments the family goes under greater stress when the individual is depressed putting normal family behaviour at risk, and this becomes an even greater challenge as parents become

* It is a genetic disease present from birth that involves an extreme eating disorder, poor muscle tone and lack of bodily sensations and limited intelligence. For more information see MedlinePlus, a service of the National Institutes of Health, USA in http://www.nlm.nih.gov/medlineplus/ency/article/001605.htm

elderly and less able to take active responsibility for the person with Down syndrome. Interestingly in some families where the individual with Down syndrome has remained healthy and has an active life style the individual is often a help for their parents who are aging (e.g., providing help in shopping, making beds, and providing social stimulation particularly when one parent has lost their spouse). So we have two situations as families age – 1) in which the child with Down syndrome may be a support, and 2) in other cases, early dementia sets in for the adult child, additional help and support is required. Parent associations need to discuss these issues, and services need to be available to make appropriate diagnosis, but importantly, observing and noting the types of support the family including the person with Down syndrome requires. Much of this support may be provided through extended family members, parent associations and with the guidance and support of local services.

It is some of the above issues, which have been looked at and are continually requested by parent associations. It becomes very important that parents of children with Down syndrome (whether of child age or adults) are linked in with Down syndrome associations. If we are able to effectively support the family and provide necessary services, considerable gains are possible for everyone. (See recommendations at the end of the chapter). It is important that teachers and medical practitioners, social workers and other professionals learn about the nature of Down syndrome. There is increasing evidence that the performance level, in terms of general intelligence, and socialization including education have all been improving in the most economically advanced countries for people with Down syndrome, and as a result parents and siblings see the rewards and effects of this, which makes a very positive difference to family life.

Employment and inclusive adult life for people with Down syndrome is still inadequate in all countries though some interesting attempts are taking place in term of employment for people with Down syndrome (see previous chapter on quality of life for individuals with Downs syndrome). Such developments when they take place are seen as rewarding for parents and a reduction of daily responsibilities where the adult child formerly remained at home.

Therefore, basic education programs which can provide support at a practical level are important. But often this can be done by community, by religious organizations, by support groups within the community, by ones neighbours and by other relatives. However, it is imperative that organised local and national services are developed if people with Down syndrome are going to reach an optimal standard of quality of life. The following summarises some of the major issues and requirements noted by parents and professionals in various parts of the world. They are found in most countries though the challenge and level of need may be met in some countries more than others.

SOME MAJOR ISSUES AND REQUIREMENTS RAISED BY FAMILIES

- In many parts of the world families with a child with Down syndrome have increasing support for their child particularly in the early years of life. Children are living longer so families have the joys and challenges associated with their child's lifespan. This means there is a need for more and broader range of services but also many more successes.
- Perceived family quality of life, across life domains, where there is a child with Down syndrome is lower than in families without a child with disability.
- Leisure and enjoyment of life is rated quite highly in over half the families
- The quality of life overall appears higher than in other instances of disability particularly when there are major emotional difficulties or multiple disabilities.
- There is some evidence that family relations are regarded as satisfactory or very satisfactory in most families and rather similar to families without a child with a disability.
- There is some evidence that many families feel they are satisfied in terms of spiritual and cultural beliefs but a noticeable number find a lack in these areas.
- Families in almost every country that have a son or daughter with Down syndrome often get little practical or sufficient emotional support from relatives, neighbours, and friends.
- Many parents with a child with Down syndrome find family finances raise difficulties.

- Most Down syndrome families are not satisfied with aspects of disability services, even in countries that have many services. This seems particularly to relate to the support given to other members of the family.
- Many parents with children with Down syndrome rate employment and preparations for careers as less than satisfactory.

CRITICAL AND MAJOR RECOMMENDATIONS TO HELP PARENTS

There is a need for action on the following major areas:

- Increased family income particularly where there is gross poverty,
- People (members of parent associations, professional personnel, a friendly neighbour) who can listen to challenges and the difficulties that families face. The request by the primary carer (generally mother) for this kind of support is one of the most common requests made regardless of country. The carer wants someone to listen to them, to off -load the problems and concerns. At this level the carer does not want lots of answers. It is a means of relieving stress and " getting it off one's chest". There is evidence that fathers would also benefit from such a resource.
- Respite facilities or a relief carer are required that suits the family circumstances (that is, the respite needs to be sufficiently varied in terms of time availability and duration).
- Parents also need respite for time to recoup or to go out with their spouse or for longer periods to get a vacation. Many have never had time for these aspects for a very long period. They also need time to give attention to siblings and spouse. This is critical for family stability.
- Family members need to be included in local community in a normal fashion (invited out for parties, and local events).
- Employers need to understand and accommodate the essential needs of the family- e.g., part time and if possible flexible working hours. For example, time to deal with issues at the child's school.

WHO SHOULD PROVIDE THESE SUPPORTS?

- Governments and agencies should be encouraged to build policy to deal with these and allied issues. It means consulting with a broad range of parents and building policy from the frontline upwards, taking into account the needs expressed by parents.
- Parent associations should help with the above in advisory roles, with local parent input, while providing seminars and workshops where knowledge can be imparted to parents and frontline and allied personnel. Parent agencies also need to provide advocacy at several levels, e.g., advocate for child and for parents, and advocate for professional development.
- Universities and colleges should be encouraged to run courses relating to disability and family needs.
- Research in Universities, supported by parent agencies and programmes, should be encouraged to work towards applied research on the family needs and demonstrate effective support through assessment including demonstration through pilot projects. This is now carried out in a number of countries.

RESEARCH NEEDS

- Clarifying similarities and difference in family quality of life among families in various cultures around the world.
- Contrasting family quality of life for families with and without children with Down syndrome and other special needs.
- Contrasting family quality of life for families who have children with Down syndrome a) with mild and b) severe and complex disabilities.
- Exploring and describing the best measurement methods to express family quality of life.
- Developing a theory of family quality of life.
- Developing relevant policy and applying practical support methods based on family quality of life evidence to help families improve their lives.

4
FRIENDSHIP FOR PEOPLE WITH DOWN SYNDROME

Roy I. Brown

INTRODUCTION

This chapter is an adaptation of an already published work* Friendship is important to all of us. Without it we face problems of isolation and at times feelings of rejection. Friends are important for our social life and psychological wellbeing, and often critical at times of stress and challenge. At other times our friends' knowledge and experience help us to solve difficulties and challenges. I am sure you can add to the list. All of these characteristics are relevant to people with Down syndrome whether they are children or adults.

Most of us get support from our friends to different degrees, and the relationships are reciprocal and varied. We like particular individuals' company and wish to share events, ideas and activities with them. We enjoy our friends' company and learn from them as well as giving to them. Variety in friendships increases our understanding and our range of skills and experiences. Friendships develop naturally for most of us, first with the support of parents and family and through the places we go, particularly school and work. This is not always as straightforward or natural when disability is involved, but the aspects noted above are no less important.

THE WIDER ASPECTS OF FRIENDSHIP

However, friendship is much more than I have stated or implied. There are many social and psychological developments that are encouraged as a result of friendship and we do not always think of

* The text was written in 2009 for in Hand-in Hand quarterly newsletter, Down Syndrome Research Foundation (2009), Volume 14(1&2). We are grateful to Ms Dawn McKenna, Executive Director DsRF, Burnaby, BC, Canada for permission to republish it here with minor editing

these. Lack of friendship restricts social and psychological development. Many people with Down syndrome are deprived of these opportunities for a number of reasons. They are often seen, and see themselves, as different from other people*. Further, parents and other family members and professionals often believe that they must protect people with Down syndrome from inappropriate friendships or arrange and supervise their friendships carefully, though most of us know from our own development that we sometimes make inappropriate friends and yet learn from these experiences, just as we learn more positive things from solid and appropriate friendships. Many of us believe it is important that people with Down syndrome experience the same type of benefits and challenges, both the positive and the negative. There are ways in which this can be done which reduces the likelihood of risk, but encourages development and maturation.

DEVELOPING FRIENDSHIP AND QUALITY OF LIFE

In discussing ways to develop friendships and provide opportunities so that friendship can be nourished, it is important to have an approach or model. Quality of life is such an approach. It has become a popular phrase, but quite often people do not understand the nuances that are involved. Quality of life, as noted in an earlier chapter, includes concepts like life span and is developmental. Enhanced quality of life requires normalized environments. It requires inclusion in normal society with its positive and negative attributes. We also need to recognize that quality of life is a holistic process, that is, it is interactional - for any one thing or process affects every other thing or process. Quality of life requires our formal recognition and understanding that many things that we do in our lives, but often without thinking about the intricacies and complexities involved, have to be thought about and planned for people who have Down syndrome, if friendship is to develop and thrive.

Friendship is part of development and learning. We are increasingly aware that such development appears associated with changes in the brain, which can enable us to become more

* Has anyone asked them how do they see other people?

effective at what we do. What are some major attributes of friendship that enable holistic development to take place?

Friendship can encourage:

a) Language development,
b) Improved attention,
c) Greater learning capacity,
d) Increased motivation,
e) Memory improvement,
f) Faster reaction time.

Developing friendship would, therefore, seem likely to encourage more able behaviour and foster intelligence. This can take place when there are opportunities for a normal lifestyle with its social and community inclusion. There are now many more opportunities to bring this about because people with Down syndrome have longer life spans, and there are opportunities for inclusive education and improved health intervention. However, we now need to do more to improve social learning. Obviously some individuals are able to develop friendships to a greater degree than others, but increasingly we see people with Down syndrome making considerable social improvement, with some entering open employment, along with effective community and family living.

What can individuals with Down syndrome gain from effective friendship?

a) Learning how to make appropriate social choices,
b) Developing appropriate public behaviour,
c) Improving social decision-making,
d) Gaining knowledge about one's local environment,
e) Increasing contact with people beyond one's immediate family,
f) Learning about one's community,
g) Improving use of one's time,
h) Learning how to interact with people,
i) Learning how to mediate social relations and behaviour (including appropriate and inappropriate relations),
j) Recognizing and setting up appropriate boundaries.

There is a further aspect of personal development, which is influenced by friendship, the area of emotional development. This includes:

a) Developing positive self image,
b) Dealing with emotional behaviour,

c) Controlling inappropriate feelings,
d) Experience in feelings of affection,
e) Dealing with one's mood, whether positive or negative,
f) Being able to express feelings in words so that people can understand how one is feeling,
g) Finding how to deal with these issues through personal insight.

Mainly the positive aspects of friendship have been mentioned and only briefly some of the negative aspects, which have affected all of us from time to time. Making friendships can make us more vulnerable and can lead to psychological and sometimes physical abuse. Parents and professionals sometimes feel they must take charge of making friends and deciding who is and who is not appropriate, and what activities are appropriate or inappropriate when people with Down syndrome are involved. But there is necessarily a happy medium, which has to be struck between choices to be made by the person with Down syndrome, and parental and professional awareness, and support.

Finding the best environment

We cannot bring about or encourage friendship effectively unless there is a suitable environment for experience and learning to take place. The process is a developmental one and ideally starts as soon as a person is born. However, it is never too late to encourage and support an optimal environment. The major aspects of development need to be understood by parents and professionals before they can effectively encourage support for friendship in an optimal environment.

What is an effective Environment?

An effective environment varies in relation to the individual's age, ability and growing experience, but in general terms is one where one can mix with peers, which include people with and people without disabilities. There are challenges, but there should also be adequate support. Support is a difficult concept because one person's support may be another person's control and restriction.

For young children an optimal environment generally includes:

a) An integrated preschool or school,
b) Playing with other children of a similar age and with similar interests,
c) An appropriate and healthy school environment with teachers and principals who understand the requirements in general, recognize the specific challenges often associated with Down syndrome, and are able to effectively model supportive interactions.

On the home front it means: Parents who understand their child's needs, abilities and challenges and the need for opportunities for growth. This, of course involves love and care but it also increasingly means choices made by the individual with Down syndrome in order to stimulate his or her development.

This implies that parents need to observe, consult and find out the best places for a child with Down syndrome. It is not sufficient to believe in a normal or inclusive environment. An environment has to embrace sensitivity towards a particular child's needs. Because children are variable, like the rest of us, sensitivity is required that will do justice to the developmental requirements of each particular child. This is an ideal, and each parent will need to work towards this end.

As children grow the environment changes. Parents need to keep an open mind about how successful the child might become. Many do better than expected and better still when support is consistent and directed to areas we know are important. For example some parents then become very concerned and worried if, like other adolescents, their children with Down syndrome want to make mature and independent relationships with others as they grow into adulthood. Teenagers and adults will likely become interested in special friends and feel strong personal attractions and sexual urges. This is, of course, very normal development. They may be interested in partnership and marriage. Parents who do not believe this is an open possibility are likely to be disappointed if they have encouraged inclusive activities across the earlier years and their children, having developed, want more choices and less controls - like children without disabilities.

SOME PRACTICAL IDEAS ABOUT FRIENDSHIP

Interests.

One of the things we know about friendship and children and adults with Down syndrome is that their interests are very similar to other people. Denholm (1992) notes that adolescents with Down syndrome enjoy the same leisure interests as people who don't have Down syndrome, and they join in these activities if they have a chance. We also know that they know what things they like, and are at their best when encouraged to make choices and gradually develop particular interests. Expression of these attributes tends to lead to friendship. So bearing in mind what was mentioned earlier it seems sensible to start with finding out what an individual enjoys, what they would like to do, where they would like to do it and who they would like to do it with: a sort of wish list. (See Brown, Bayer and Brown, 1982). We also know that people with Down syndrome tend to make friends with other people with disabilities. This partly occurs because they frequently mix with such individuals, but it is also because they are in a similar position to them (McVilly et al, 2006a, 2006b, 2006c). Yet there are many instances, particularly when they live in integrated settings, where friendships occur with a wider range of people. Sometimes such friendships are one sided, which can cause disappointment, anxiety and withdrawal. Listening and supportive understanding are required as well as empathy with differences, challenges and future opportunities.

Leisure and recreation.

It is important that friendship is given opportunity in positive though not perfect environments. Challenges are part of becoming more mature. Leisure and recreational activities are sure-fire ways of meeting people where friendships can be made. Many young people with Down syndrome are good or interested in sports, such as swimming and gymnastics and this has proved an excellent way to make friends. Many of these young people go to competitions travelling far and wide to events in different countries. This alone builds up experience and things to talk about, and to talk with others with whom they compete. Competition heightens awareness and interaction.

The Internet.

These days youngsters can use the Internet and keep up communication with friends they meet at events. The Internet is a means of keeping up friendships but one needs to learn how to use it appropriately (see Ryba and Selby, 2004). Friendship circles using the internet links to Down syndrome groups (try your local Down syndrome Association) or groups who share interests are now means of making contacts and learning at the same time.

The arts.

Another avenue, which has proved popular is the arts, particularly painting, dance and drama. The skills demonstrated by many young people with Down syndrome are often considerable. Around the world a number of people with Down syndrome have been particularly successful, and some move from leisure to employment in these fields. In most cases, and equally if not more importantly, they develop skills, gain praise and applause and improve their self image, making other developments possible. Some of these individuals do this with others who have similar disabilities or challenges. Others perform or practice in integrated settings. (The Magnus Family, 1995, Burke & McDaniel, 1991)

Further education and friendship.

Some youngsters with Down syndrome go to college and university. The authors of Tertiary Education (Hughson & Uditsky, 2007) indicate that attendance at tertiary institutions, in integrated and inclusive setting, brings about better self-image, important skills and more friends, including those without disabilities. To date only a few people with Down syndrome go such a route, but what impresses is that the parents of such students often refuse to believe the limiting predictions of some professionals. These parents also became amazed at how well their children developed. The fact is that learning is holistic - if you want friends then you have to try out many things and frequently the activities are based on the individuals' own choices. There will be many whose achievements will be limited, but the strategies and tactics are the same – opening the door to experience, providing support,

allowing the expression and discussion of choices and supporting and respecting these. If you don't think something is possible test it out with support, it will often work and if it does not work, try another way. Sometimes parents, for all sorts of reasons, do not have time. In this case the development of a circle of friends chosen by the child or adult with support from parents or primary carer can be helpful. One reason is that a body of supporters reduces isolation and broadens contact beyond the family.

So far the chapter discusses some of the background to the development of friendship, the importance of friendship in developing other skills, the relevance of personal choices, and the support of parents and others. Below some challenges about friendship are discussed along with possible solutions, including such issues as the difference between friendship and friendly, and how individuals make such differentiation - sometimes a challenging issue!

NATURAL FRIENDSHIPS IN NATURAL ENVIRONMENTS

Developing friendships can give rise to a number of challenges but for the most part these are not very different from those found for people without Down syndrome. Development may be slower and greater support is frequently required. However many young people with Down syndrome create stable and lasting friendships and in a small but increasing number of cases these can lead to marriage or partnership.

With all relationships there will be challenges, rewards and sometimes sadness.

Natural environments often provide greater ease of learning and experience of how to handle challenging situations, and also lead to transfer of skills, particularly when friendship is rewarding. In natural environments friendships frequently develop from other activities; play activities when we are young, from interaction in school, and with neighbours' children down the street. Some of these friendships can last a lifetime. When we are older tertiary education, employment, religious organisations and recreation activities often provide the background for new friendships. You probably can think of many other places where friendships develop. The question is can children with Down syndrome develop friendships in the same way? The answer is that they can

and do if placed and interact in those environments but the development may be slower and have their own set of challenges. We now look at some of these challenges and some of the ways of dealing with them. In a few cases the issues are more complex and require some counselling both for the child and the parents. Parents should not hesitate to seek counselling from someone who is knowledgeable about social behaviour and Down syndrome. We all need help and advice from time to time, regardless of our situation.

DEVELOPING FRIENDSHIPS

Although we may develop friends at any age, opportunities in early life often provide the structures, which enable us to make and keep friends over a long period of time. When we are young, friendships tend to develop during play. As we know from the work of Piaget (1962) play is at first solitary, then children play in parallel and eventually move to cooperative play where they interact and begin to share toys and activities and also experience challenges that arise when there are conflicting needs or intentions. It is therefore sensible to provide opportunities for play with other children as soon as possible. One of the challenges that can arise is that children with Down syndrome may arrive at a particular stage at a later time than other children, so that their behaviour is not synchronized with their peers. This is one reason why early intervention in a pre school integrated settings is so critical. They enable many children with Down syndrome to keep up with their peers in terms of social behaviour.

If a child does begin to lag behind, extra opportunities such as modelling from parents and others become very important. In the first few years of life minor discrepancies are less important than giving children opportunities to go through normal developmental stages in inclusive settings. Some parents wonder if it would be better for their child with Down syndrome to stay in closer touch with other children who have similar challenges and although it is important for mothers and fathers to be involved with parents who experience similar challenges it is also important that families with children who have Down syndrome mix with other families frequently going, for example, to each other's houses so their children can play together. Parents need to assess

environments and the influence they are likely to have on their child, and it is always important to have in mind long-term goals. Thus what is easier to begin with may not be what is in the child's best long-term interests. It is important to keep in mind the importance of inclusion and the relevance and critical nature of long-term development. As indicated previously, it is dangerous to predict how far children will go.

Preparing for friendship can be enhanced by the development of a range of other activities such as family games, leading on to shared games on the computer, joining group activities such as sporting clubs, drama, dance and music where individuals can develop skills in which they are interested and often this can be carried out in an inclusive environment. Joining scouts, guides and like groups can, as children develop, be effective ways of making friends

FRIENDLY AND FRIENDSHIP

Children need to learn to recognize who are their friends and to differentiate between "friendly" and "friendship". People who interact with a person kindly and respectfully are likely to be friendly. To help a person is friendly. Friendship is based on these attributes but mutual attraction and familiarity over the long term are attributes that are necessary for friendship. These are abstract ideas and can be difficult to explain and teach. They are also ones which are understood more clearly as people move into adolescence and are important for independent living. Giving examples from one's own experience can help. Young people with Down syndrome need more help than most people in this area partly because potential friends might be less readily available and the need is high.

In this context parent behaviour is particularly important and through positive parent interaction with their own friends and their friends' children, as well as mixing with siblings' friends modelling can be very effective. Attending inclusive educational programs and taking courses in friendship, which are provided by some Down Syndrome Associations can help to clarify such differentiation. In this context it is useful for parents to have a list of desirable requirements and criteria for any course or program to which they may send their child including the types of behaviour

they would like to see their child develop. Programs differ in standard and teaching competence and therefore it is necessary for parents to get a clear idea of what a program involves and how it is to be taught. There needs to be a match between what a child needs, what a parent is comfortable with and what is being offered.

ENCOURAGING APPROPRIATE SOCIAL BEHAVIOUR LEADING TO FRIENDSHIP

As children develop so occasions arise when inappropriate behaviour occurs. For example, the older the child, the more apparent are infantile responses. Examples are inappropriate responses to people the child does not know. This can include going up to strangers and wandering off in shopping centres or other crowded places. Inappropriate touching which may at times offend and by others be seen as "cute", can on occasion get the child into difficulties. Interestingly, much of this type of behaviour can also be observed in children without disability because of poor social examples or very strong needs for affection, and can lead to inappropriate relationships.

It is important to set up appropriate boundaries. With effective modelling and verbal and nonverbal examples from parents, such behaviour is likely to lessen. It may also be necessary to explain to others what you are trying to teach and why. This applies to friends and relatives, including grandparents, who sometimes do not always recognize the need to teach such boundaries. Play and support groups organized through various Down Syndrome Associations, and specialized services (such as the programs provided at the Down Syndrome Research Foundation), can also provide help and teaching in such circumstances. Siblings are often able to model and teach appropriate social behaviours to their brother or sister with Down syndrome because they are often fairly similar in size, are reasonably close in age and have a bond with their brother or sister. Where this happens other friendships are likely to be formed more appropriately.

The development of social skills is an important prerequisite to all friendship and should be initiated as soon as possible. Children should become familiar with neighbours, and know the location of "safe houses". They need to become traffic-

wise. Such knowledge and allied skills can make the road to friendship easier. Down syndrome associations around the world could do more to promote such activities because schools, though they may include such training, do not as a rule provide sufficient practice and learning in real life social situations so these activities become second nature.

As children move through the school's cycle a number of other challenges can occur. Having developed friends at school, particularly during the secondary school cycle, issues can arise when, on leaving school, individuals take different paths. When young people aged 18 or 19 years of age go off to work or college, their peers with Down syndrome, who are of similar age, may go to training workshops or other segregated placements. At this point it is likely that friendships will be broken or much diminished. This is one of the important reasons why we must move to lifelong inclusion. To have inclusion in school which then is disrupted as adulthood approaches, creates difficulties for people with Down syndrome, particularly if they have been showing favourable development over the childhood years. Such broken relationships can result in poor self-image and in personalities which may be so inclined, to depression in the adult years. Feeling included and accepted is a lifelong process and is critical to the development of empowerment, positive self-image and sustained motivation. Down syndrome Associations and programs for people with Down syndrome need to keep this aspect clearly in mind and it is a challenge that has not yet been met.

Friendship and the Development of Adult Activities

Employment is one critical way of dealing with such concerns and opportunities provided by such firms as McDonald's, shopping centres and hotels can be good examples of where both employment and friendship can be developed particularly if earlier social development has been positive. (See Capie, Contardi & Doehring, 2006).

For a few and a growing number of people with Down syndrome opportunities for college and university are now beginning to develop more extensively than in the past. These often provide opportunities, if courses are inclusive rather than separate, for normal friendship as well as learning and sometimes

later employment (See Hughson and Uditsky, 2007). In these instances a number of actions are required. First, children should have developmental opportunities during childhood where inclusion is maximized. Second, the family and school need to be future oriented, and, third, support the individual's own interests. Students with Down syndrome need to be provided, where appropriate, with opportunities to visit colleges and universities while still at school. Parents need to be encouraged, as do siblings, to provide an environment in which ideas and development can be considered. This will not be appropriate for every child with Down syndrome and at the present we are talking about a noticeable but increasing minority, but since we cannot predict accurately the amount of growth that is going to take place it is important that we leave the door open. Finally Down Syndrome Associations need to work with professionals who have knowledge of such developments and encourage their expansion.

Social media will play an increasing role in our society and it can be a means of meeting needs for friendship. Children should start learning about computers as early as possible. A number of young children with Down syndrome can quickly become computer efficient in terms of the basics. Friendship programs are available and with careful selection of choice for age and ability levels these can prove useful. (See Ryba and Selby, 2004). As children use computers more extensively opportunities to e-mail friends becomes a regular activity. Many teenagers and adults with Down syndrome make use of resources like Face Book which is becoming much more user-friendly, but it is important to keep an eye on what they are doing, but as they age not too obvious a one! Some families enlist the support of a cousin/ aunt/ uncle to be a Facebook friend, enabling monitoring without overly intrusive observation.

A few Down syndrome organisations are promoting dating services controlled by their own personnel. Yes, inclusion means the use of such activities for a number of young adults. This is a good example of making use of normal societal communication while controlling and monitoring the interactive process.

As children age, and particularly during their teens and early adult years, they can be embarrassed by parental presence and commentary in the presence of friends. Sometimes comments are necessary. This is also true of all people with Down syndrome (and not just Down syndrome) and therefore sensitivity towards this aspect is a good idea. Also as they age many wish to go out on their own. If they have learned to use public transport, are familiar with the neighbourhood, are developing a sense of social boundaries, and have a cell phone and can easily call appropriate people in case of need, then such outings should be encouraged, gradually giving permission to increase the range, the variety and duration as learning takes place. It is natural for parents to be concerned about some of this and anxiety is appropriate. This is true of all parents but sometimes becomes more apparent when parents have had to structure and monitor things intensely over a long period. Recognizing one's own responses is important and in this context there is a need to encourage a child's developing independence and override undue concerns. However the definition of 'undue concerns' is very personal and for this reason it is a good idea to observe what other parents do and to discuss with them the challenges that they also face. This is another good reason for belonging to a Down Syndrome Association and also attending conferences relating to Down syndrome where such issues are often the subject of presentations and discussion. It is natural to feel concerned when children go out without a parent or sibling with them, and even more so when we know that the child has had challenges in the past and/or has limitations now. Friends can protect and support by going out as a group.

One of the challenges of being in inclusive settings is that bullying may occur. However, as one mother of a child with Down syndrome noted, she preferred him to go to a normal school with such challenges so that he would learn to stand up to other people as he grew up (see Lawrence et al, 1993). Looking after ones self is a difficult and complex task to learn but pays dividends in the future.

As children with Down syndrome enter adolescence and early adulthood they are likely to become sexually attracted to others. Having developed a wide range of friendships prepares them for this development. Once again personal and developmental education, which includes sexual education, should ideally be a natural process which is on-going through the life of the individual. Programs are now available, though they differ in quality. Here again appropriate social behaviour knowledge of boundaries, and adequate language to express one's thoughts and feelings can always enhance an individual's ability to develop special friendship which may lead to marriage. One excellent program is from Australia (The Right to Know Program, 2004).

Activities during mid-to-late adolescence and adulthood often include going out for walks with one's boy or girl friend, going to the cinema or theatre, looking at television, and sharing in a wide range of other activities which are mutually satisfying. Fortunately we have reached a time when natural social development is acceptable for people with Down syndrome. Such relationships often bring mutual support but can give a lot of heart searching for parents who may receive both negative and positive advice. The critical issue is the satisfaction and happiness of the two young people concerned. Partnership and marriage are likely to require parental and often professional front-line support, but information to date suggests that such relationships are often very positive, enabling the couple to do a wide a range of activities which would not be possible on their own.

What has been described is an extension of friendship and a major aspect of inclusion, which is now seen critical for many people with Down syndrome and other disabilities. There are still parents who do not approve of such relationships and there are many young adults who are not ready because they either do not have the skills or the inclination to make this possible. However experience suggests that many more are capable than we previously thought. Marriage and/or partnership is also a natural progression of the inclusion process and it can be strongly argued that one cannot have a "bit of inclusion", because as people grow and develop, know that they have choices and can control aspects

of their lives, they will press forward to ensure full inclusion comes about.

Showing interest in your son's or daughter's activities is, of course, important, but too many questions or verbal advice can sometimes be inhibiting. Further, people with Down syndrome tend to respond best to visual and tactile interaction along with short and simple sentences. Long commentary often confuses and does not seem to be registered as well as what they see or feel. Eye-to-eye contact, followed by a slight touch on the arm, often achieves the desired effect. Treating the individual as an adult even though they do not always behave as an adult promotes good modelling and encourages copying. When there are challenges positive commentary without deep inquiry can help to encourage positive feelings while delicate inquiry, which is private, can often elicit the reasons for negative changes in behaviour.

An Illustrative Story

RB first heard of Krystal through his daughter who was directing a play in Toronto. Amongst the young actors was Krystal who was the first person in the cast to learn her lines. Krystal has Down syndrome and had previously played the role of Phoebe in the TV-movie version of the bestseller The Memory Keeper's Daughter*. I was put in touch with Madeleine Greey, her mother, who says, "Krystal has gained so much from the world of theatre, which is the most inclusive place she's discovered". Indeed the inclusive environment gave Krystal the opportunity to meet a wide range of people. Her mother describes the learning and challenges involved. She also describes her own excitement and anxieties. The result was a roaring success. In real life Krystal wants to continue as an actor and eventually get married. Mom says, "If anyone had said when my daughter was born that she'd star in a movie, I would've

* This is a play about a family's secret drama. A perfect couple is about to have their first baby, but a snow storm prevents them from going to the hospital. The husband is a doctor so he decides to have the baby at home, aided by his nurse. Twins are born, first a boy and then a girl (Phoebe), who is born with Down syndrome. Instead of sharing the news, the husband decides to tell his wife that the girl was born dead and asks his nurse to institutionalise her. Instead of doing so she decides to keep the baby for she has lived alone all her life, and finds happiness with her. The rest of the family has different sorts of conflicts. The play demands intense performances, and it is Phoebe who has the leading role.

laughed the words away. Doctors said she might not learn to walk, let alone get out of diapers or feed herself. People with Down syndrome generally are able to do more than anyone imagined!" (Greey, 2008; Edwards, 2006 and 2008).

Photography of Krystal at the Hollywood premiere of The Memory Keeper's Daughter taken by her brother Nick Nausbaum. Reproduced here with Permission.

5

ON EDUCATING THE CHILD WITH DOWN SYNDROME

Rhonda Faragher

INTRODUCTION

Education is a fundamental human right. One of the most rewarding aspects of parenting and teaching is the opportunity to pass on the wisdom of ages to the next generation. Education for people with Down syndrome is critically important and has been recognised by the United Nations in the Charter on the Rights of People with Disabilities. In this chapter, we will explore best practice approaches to educating learners with Down syndrome across the life span. People with Down syndrome can expect to live a long, healthy life and each stage of development provides opportunities to enrich individual and family quality of life through education. High quality early education opportunities can build a strong foundation for further development. Throughout the school years, access to the academic curriculum is vital, particularly in mathematics and language but also science, social science, citizenship education, creative arts and physical education. Until recently, post-school options for people with intellectual disabilities were limited and with that, opportunities for further education. This is changing around the world and examples of practice are offered here. This chapter includes strategies for teaching and learning as well as references to further information and resources[*]. The author, Rhonda Faragher, writes:

"When my daughter, Ruth, was born with Down syndrome in 1996, I was a secondary mathematics teacher. I knew almost nothing about Down syndrome, not even what her life expectancy was. Although I had been a teacher for over a decade, I had never taught or even met a person with Down syndrome. In those early days, in addition to trying to establish breastfeeding and ascertaining her

[*] It is convenient to mention the importance of informing parents about the different schooling options available in their community and develop a spirit of collaboration with the school in order to build a team with teachers and provide the necessary support at home thus achieving the best benefits for the present and future of a child with Down syndrome (MG)

health status, I realised I had no idea how to teach my baby mathematics! Now it does seem strange to be worrying about maths so soon but I was anxious to give my daughter the very best start I could. It seemed natural to think about her education along with all the other early intervention activities".

At the end of the 1990s, almost nothing was known from research about mathematical development of individuals with Down syndrome. Early literacy, including teaching reading, had been researched in greater depth. Most other areas of education for learners with Down syndrome remained under-researched. Since that time, researchers and practitioners around the world have slowly been adding to our knowledge of how to teach students with Down syndrome (Faragher & Clarke, 2014b). In this chapter, we will offer suggestions from research and practice to help those who teach people with Down syndrome – that is, teachers, parents and other carers. We will work through key stages in the lifespan. It is important to acknowledge that people with Down syndrome have a life expectancy into the 50s with one in 10 people living to their 70s (Torr, Strydom, Patti, & Jokinen, 2010). Education is an important way of preparing for a long, productive adulthood.

INCLUSIVE EDUCATION OF LEARNERS WITH DOWN SYNDROME

Inclusive education, the practice of 'welcoming, valuing, and supporting the diverse learning needs of all students in shared general education environments' (Thousand & Villa, 2000, p. 73) is of critical importance for learners with Down syndrome. A number of research studies (Buckley, Bird, Sacks, & Archer, 2006; de Graaf, van Hove, & Haveman, 2013) have indicated the power of inclusive education for academic progress. It is important to acknowledge that the research does not say that students will not learn in special school settings; it does say, though, that students will make more progress when included in classrooms and engage with lessons along with children of their own age in regular schools. The research also indicates that other learners in the class without disability will have enhanced education outcomes, too.

Inclusive education is not easy to achieve, but it is also not impossible. Before looking at learning across the lifespan in the following sections, here we will explore inclusive school practice and consider what is needed to ensure the best education outcomes.

This will be addressed through three important issues: resources, strategies and attitudes.

Resources

Most learners with Down syndrome do not require expensive equipment, facilities or other resources to be able to learn effectively in school. Alternative curriculum programs usually are not needed, either. As we have noted, research indicates that learners with Down syndrome achieve better education outcomes if they are taught in inclusive classrooms. An additional bonus is that the learning of the other students in the class is also enhanced. So rather than being a cost educating learners with Down syndrome in regular classrooms is more effective, and cheaper than maintaining a regular education program and a special school system.

Sometimes, school systems or parents are anxious that funding needs to be available to pay staffing costs for teacher assistants. While support for teachers to enable sufficient time for planning is important, and in some cases, assistance with class management is helpful, inappropriate use of teaching assistance has been shown to be detrimental for learners (Giangreco, Edelman, Luiselli, & MacFarland, 1997).

Appropriate use of teaching assistance involves allocating the assistance to the teacher, rather than the child. Teachers remain responsible for the learning of all the students in their class. The teacher assistant works under the direction of the teacher to provide assistance. This might take the form of:

- working with a small group of students who are high achieving and needing extension
- supervising the whole class completing work set by the teacher while the teacher works with a small group of children needing extra support
- assisting the learner with Down syndrome to work with classmates to complete tasks assigned to the whole class
- preparing materials for use by the student with Down syndrome in forthcoming lessons

At the heart of the challenge of appropriate use of teaching assistance is the predisposition of learners with Down syndrome to develop learned helplessness (R. Faragher & Clarke, 2014b;

Wishart, 1993). Children, from a very young age, have been observed to opt out of activities when they believe others will do the tasks for them. Rhonda Faragher remembers her daughter, Ruth's, preschool teacher relating an experience she had observed. There was a new assistant in the room and she was writing Ruth's name on her artwork because Ruth had appeared not to be able to do this when asked. The teacher walked past and said, 'Ruth! You know how to write your name. You do it!' At which point, Ruth picked up the pencil and wrote her name without a problem.

The reasons behind the prevalence of learned helplessness have been hypothesised (Faragher & Clarke, 2014a). Certainly, the behaviour has been observed in very young children – even babies – so some innate cause is plausible. However, it would appear there is a learned aspect as well. For children who find learning difficult, their experiences are likely to include more failure than success. It is, perhaps, understandable that avoiding the risk of failing is better than attempting a task, particularly if there is someone on hand who will take over if they wait long enough. Those involved in educating students with Down syndrome can help learners overcome these behavioural tendencies by providing the minimum support needed, using strategies such as 'I'll do one, then you do one', and keeping careful records of previous achievements. As children grow older, teachers and family members can speak to the student about their thinking. For example, they might say, 'Yes, this is difficult to learn but remember how hard it was to learn to ride your bike but you worked hard and you did it! I will help you learn this, too.'

Strategies

Many teachers feel unprepared to teach learners with Down syndrome. Fortunately, there is no evidence that a special approach is needed that is different to the other children in the class. Indeed, approaches and strategies that have been shown to be effective for learners with Down syndrome and other intellectual disabilities have proved beneficial for others in the class as well (Boyle, Scriven, Durning, & Downes, 2011; Tait, 2014).

Learners with Down syndrome are known for their strengths in imitation, social interest and for a preference for visual

learning modes. These strengths can be used to enhance learning. It is important to note that visual learning does not imply only the use of photographs or images. Printed text is also visual. Children who have learned to read are able to use written instructions to guide their learning. In mathematics, use of symbols to record operations is valuable. Calculators that display the entry and not just the answer are available and effective. Further examples of strategies are offered in the sections following.

Attitudes

A fundamental pre-requisite for successful inclusion in schools is the attitude of school personnel, peers and family members (De Boer, Pijl, Post, & Minnaert, 2012). The attitude of the principal is known to be important (McGregor & Salisbury, 2002) and can influence the outcome of problems that arise. For example, if a teacher is experiencing difficulty with a student, the principal may use the situation as evidence of why the child needs to go to another school such as a special school. Alternatively, the principal may take the view that the child is a member of the school and assist the teacher to develop ways to better support the learner. This could be through sourcing expert advice from a learning support teacher, identifying professional development opportunities for the teacher, or providing additional assistance in the classroom to support the teacher.

For teachers, too, attitudes to inclusion are important (De Boer, Pijl, & Minnaert, 2011). Previous study in inclusive education can be helpful in preparing teachers for their work with diverse learners and in countries such as Australia, all pre-service teacher education programs for some years now have required the inclusion of at least one subject in diversity. In addition to specific training, creativity and flexibility in thinking are also important. One teacher developed a program for teaching Shakespeare to a learner with Down syndrome who had a limited reading level. Through the use of film and audio books, she was able to support the learner through carefully structured worksheets to prepare an essay on the play, 'Romeo and Juliet'. When praised for her innovative work, the teacher replied with surprise, 'But I'm just making this up!' For many teachers, working with learners with Down syndrome provides an opportunity for them to be creative

and explore their discipline. Many teachers have found deep enjoyment and satisfaction in what they have been able to achieve.

Sometimes overlooked is the effect of attitudes of families and their interactions with schools. Some parents may have had negative experiences in their own education and some are fearful of interacting with schools. Sometimes, parents are made to feel responsible for their child's behaviour with some being called to take their child home during the school day. Other parents have experienced the situation of having all their child's misbehaviours documented or described to them as soon as they arrive to collect their child, without hearing any positive stories. Fortunately, this is not always the situation and many parents have experienced supportive partnerships with schools where there is a sense that their child is valued and welcomed, even though there might be difficulties along the way.

On occasions, parents and families cause challenges for teaching staff. Some parents can be very assertive and can place seemingly unreasonable demands on teachers. It helps to remember that parents often have been involved with their child's education from birth – they know a lot and have achieved a lot. They are also keenly aware that they get one chance to educate their child at school. Schools can use the challenges of parents to advantage through the use of partnerships. Actively listen to the requests of the parents. Include them in conversations about learning and not just at the formal planning meetings. Be prepared to acknowledge shortcomings in the program if they are evident. It might also be necessary to explain limitations and constraints on the school. It is essential not to promise what cannot be delivered. For example, do not promise to establish a friendship program at lunchtimes if the school does not have the mechanism to do so. Through active listening to what families want schools to provide, creative educators can consider alternative approaches that can meet the same goals but in a way that can be managed by the school.

Having discussed the critically important Inclusive Education model, we now turn to a focus on various stages of the lifespan in our discussion of educating learners with Down syndrome.

Babies with Down syndrome delight parents and grandparents alike as they move through milestones. That first smile is a precious moment! Even at this early stage, important learning patterns are established. Breastfeeding has many benefits for the developing baby, including:

- development of the facial muscles, of benefit for later speech production
- optimum nutrition for the growing brain
- support for the immune system

Breastfeeding can be difficult to establish for babies with Down syndrome but with support, patience and time, most babies do learn this important skill. Information and support for mothers is available from the Australian Breastfeeding Association (www.breastfeeding.asn.au).

Early intervention is available in many countries and it can be helpful for families to have access to qualified practitioners from a range of disciplines including speech pathology, occupational therapy and physiotherapy. If these services are unavailable, parents and carers may still support their child's development through engagement in play, regular family activities and through the use of additional simple techniques.

Play

Encouraging young children to play encourages development. The most important guiding principle is that play should be fun! Follow your child's lead and let them spend time doing what they enjoy. This play could include playing with water, climbing on ladders, playing on swings and with balls. These are good activities for **gross motor development**. Balloons and bubbles are good for introducing children to playing with balls. They move slower and provide time for children to prepare movement to make contact.

Making mud pies or helping with cooking dough gives babies and toddlers opportunities to develop the muscles in their hands, an aspect of **fine motor development**. Later on, threading beads on strings and drawing on paper or in sand continues the development.

Most children enjoy music, including children with Down syndrome. Opportunities for playing with sound aids **auditory development.** Banging on kitchen pans, shaking stones in a plastic bottle, strumming a guitar, and singing lullabies are all enjoyable activities, if noisy! Later, singing in choirs provides speech therapy in an informal way. Singing phrases strengthens the muscle of the diaphragm which is necessary to support the breath column for the length of a sentence. This can be a difficulty for many adults with Down syndrome. The low muscle tone can make speaking long sentences in one breath a challenge. Singing might also assist with clarity of spoken language with the emphasis on voice production.

Many young adults with Down syndrome have demonstrated a talent in the visual arts. Most children enjoy art, including those with vision impairment. Exploring their world through art is an important way young children develop their **visual awareness**.

Play also serves the basis of **mathematical development** (Faragher, in press). Many common childhood activities stimulate a child's understanding of the world and lead to the basis of mathematics. For example, jigsaws support geometrical understanding; water play encourages measurement; board games such as 'Snakes and Ladders' encourage counting and early understandings of probability.

Spoken language

To assist the development of spoken language, babies need to learn the power of communication. That is, they learn that they can influence the behaviour of those around them through communication. An approach that has shown great value is *key word signing*. This technique involves simple signs that are used in conjunction with spoken words.

For example, the sign for *drink* could be shaping the right hand as though holding a cup and miming drinking. At the same time, the adult would say 'drink' or 'milk' or 'water'. The idea of *keyword signing* is that the same sign is used for anything referring to drink. There are standard signs in the sign language of the Deaf community. There are also adapted signs for key words (known as Makaton in some countries). These can be used or families can make up their own signs, particularly if the signs are just used for communication with each other. Signs must not cover the mouth. This ensures the young child can see what the mouth looks like when saying the word. A useful collection of first words include: eat, drink, finished, more, toilet, help, and sleep.

To teach babies to sign, adults should consistently use a collection of signs in all their communication with the baby. Many parents have been surprised that babies can understand signs months before they are able to make signs themselves. To help babies learn to make the signs, parents can shape the baby's hands while saying the word. Babies can be taught to sign as early as 6 months and some will begin to sign back from 12 months! When the child is able to say the word, they drop the sign naturally. Signing has been shown to encourage spoken language and it is a powerful technique to compensate for delays in spoken language production avoiding intense frustration for toddlers unable to communicate their needs and wants.

Language development is also supported by other activities. Babies love books! Simple, bright children's books are a delight and bedtime with a story can be a time parents cherish. Singing is also important for babies as they hear a range of frequencies – the high and low notes. As children grow, singing can be an effective form of on-going speech therapy as it helps with strengthening muscles for breathing and sound production.

Further information on speech and language development can be found in work by Buckley and colleagues.

Learning to read

Over many years, expertise has developed in teaching young children with Down syndrome to read. It is surprising that children can learn to read even before they are able to say the words. They may use signs or select a photograph to show they know the meaning of a word. Many parents have observed their child's spoken language develops alongside their reading. For example, Rhonda Faragher's daughter began using 'and' in sentences when she learned to read sentences with her brothers' names in them: 'Luke and Paul'. Until then, she had just said 'Luke Paul'. A useful review of research and practice is provided by Burgoyne and colleagues. Families looking for a guided approach to teaching

reading may find books such as ‘Teaching Reading to Children with Down Syndrome’ helpful (Oelwein, 1995). The method of Troncoso and del Cerro is of considerable advantage to Spanish speaking learners (Troncoso 2009).

Research and experience would suggest that you do not need to wait until the child appears to be ready to read – you can begin as soon as the child is old enough to match things that are the same. One approach that families have found successful is to focus on teaching sight words. These are words we recognise just by looking at them. Useful and interesting first words for a child are the names of their family, including their own.

Write the name of each family member on a white card in large letters, including capitals. Begin with the child’s name and then perhaps Mummy or Daddy.
Say:
“This says ‘Daddy’. Give the card to Daddy”.
With only text written on a card, the child must focus on the text and not pictures or some other clue to work out what the word says. Once names are known, other words can be introduced such as ‘eating’. Simple sentences such as “Daddy eating” and “Mummy eating” can then be made.

Ruth Faragher, age 4.

GOING TO SCHOOL

A proud milestone in a child’s life is going to school. The early years involve the child learning how to act in a very new context. All children need to learn what behaviours are expected in school and this can take longer for children with Down syndrome. A key

strategy is to make use of the powerful expertise at mimicry exhibited by many children. They will copy the behaviour of other children in the class. In considering behaviour, be mindful that for children with limited verbal communication, behaviour ***is*** communication. If challenging behaviour is being exhibited, try to look for the cause. What is the child trying to communicate? Are they unhappy, in pain, tired or bored? Avoid punishing inappropriate behaviour. Rather, distract the child and refocus. Give positive reinforcement of appropriate behaviour.

John has been given blocks to help with his maths work. After a few minutes he starts throwing them on the floor.
His teacher says, ‘I see you have finished with the blocks, John. Help me put them away.’ The teacher gathers the blocks (with John’s help, if he joins in). ‘John, let’s have a look at what David is doing. David, show us how you are using the blocks. John, would you like to help David?’

Further suggestions are offered by Jones and colleagues.

Early concepts

A key principle in educating school aged learners with Down syndrome is ‘follow as closely as possible the education of other learners in the class’. In the early years of primary school, all children are learning the foundations of academic subjects. This includes learning to read, write and count, along with beginning study of other subjects. Many children with Down syndrome enter schools **able to read** simple sentences and phrases. They may even be ahead of other children in their class! Some may not yet be reading but may gain interest after seeing others do so. The initial approach should still be on sight words with a focus on words of interest to the child.

Learning to write

Learning to write by hand is still important even with increasing access to computer keyboards. Occupational therapists may be able to provide assistance with games to improve fine motor coordination which is necessary for control of a pencil. Picking up small objects such as threading beads can be useful. Providing children with lots of opportunities to scribble and draw is also

helpful. Pencils, crayons, paints and marker pens are great to have close at hand, along with lots of different types of paper. Young children often enjoy writing on black boards with chalk. Drawing with your finger in mud, making mud pies, rolling 'snakes' with clay are all activities that support writing development. Writing in sand with a stick is often fun, too.

Learning to speak

Young children with Down syndrome are often still **learning to speak** in the primary years. Sometimes, they can be understood by their family but others struggle to understand. It can be easy to fall into the trap of the child not needing to talk as the family members guess what the child wants. Look for opportunities to encourage your child to talk.

For example, at meal times, set an empty cup on the table. Ask the child, 'Would you like water or milk?' You might have the words written on card and the child can choose the card for what they want. Emphasise how the word is pronounced.
'That says, "Water". Can you say "water"?'
Praise the child for vocalisations. These will become better with practice. Only provide the drink when the child has signed, spoken or read the word – that is, they have communicated their choice to you.

Early in the primary years, the foundations of mathematics are reinforced. There is evidence that leads us to know that babies are born knowing quite a bit of mathematics – a sense of quantity as well as early geometry. Our basic number sense becomes developed when we acquire language and our brains move from an approximate sense of quantity to an exact, language-based one where we connect our expanding understanding of number to a mental number-line. This development continues into adulthood for all of us. Recent research suggests that children with Down syndrome can be assisted in their development of the exact number system by focussing on the symbol that represents numbers. These symbols can be introduced early on – from two years. Later on, number-lines can be used to reinforce the order of numbers. Electronic calculators are also very helpful and children should be taught how to use them from a very young age.

To teach how to use a calculator, allow a young child to play with the calculator. Show them how to turn it on and off. 'I am going to turn it on'. (Turn on the calculator). 'I'll turn it off. Now it is your turn. Turn on the calculator.'
Next show the child how to enter a favourite number, perhaps their age. Take turns – you enter a number, they enter a number. Write numbers on paper and take turns entering the number. Check the display to point out that the numbers match.

Initially, there is no need to move to performing operations, such as adding two numbers. That comes later, once operations have been introduced in class.

Teaching your calculator to count:
Enter the starting number (e.g. 1). Press + 1 (to count in ones). Press = = = = = =. Count with the child and the calculator.
Teaching your calculator to count backwards from 20 by twos.
Enter the starting number (20). Press – 2. Press = = = = = . Notice what happens when you go past zero.

Learning to understand numbers

Learning to understand number is important but there are other essential aspects of mathematics that are also introduced in the early years of primary school. **Geometry** is one of these. This branch of mathematics includes topics such as location, space and orientation as well as shapes and their properties. Geometry links with number and measurement. Geometrical understanding can be fostered by giving young children opportunities to explore their world through playing with water and sand, making things out of old boxes and playing with puzzles such as jigsaws.

Measurement

Another important branch of mathematics is **measurement**. Money and time typically cause difficulties for people with Down syndrome so early familiarisation can be helpful. Allowing young children to become familiar with using money to purchase small items and to save for larger things can be helpful. Time involves more than reading a clock. Learners must gain a sense of the

duration of events, such as how long a favourite TV program lasts. They must also develop a sense of the sequence of events – what comes first, then next, then last in a story, for example. Understanding the telling of time involves understanding that midday is when the sun is highest overhead in the day. Clocks should give the same reading. The hands on an analogue clock also work together. It is possible to tell the time using the hour hand alone. Telling time with digital clocks appears easier – certainly it is easier to read the numbers. However, analogue clocks give a visual representation of time passing. Also it is much easier to understand what happens after the clock says 10:59 on an analogue clock., or that it is nearly 11 o'clock.

SECONDARY SCHOOL

By the time secondary school is reached, learners with Down syndrome are usually more settled in school. They are likely to have overcome earlier behaviour difficulties and be more attentive and able to concentrate for longer periods.

Puberty may raise new challenges but it is important to separate out these problems from other education matters and deal with them to prevent these problems from having a deleterious impact on learning. Some young people have been placed in segregated education settings because their behaviour was difficult only to find the special schooling helped neither the behaviour nor their education. Pain should be suspected for girls displaying misbehaviour or altered behaviour patterns. Even articulate young women with Down syndrome may find it difficult to express pain caused by menstruation or pre-menstrual syndrome. Boys in the early secondary years may need help with the appropriate expression of their developing sexuality. Straightforward discussion of socially acceptable behaviour can avoid or minimise problems that in the past have led some boys to being placed in segregated school settings where they have been unlikely to learn more appropriate behaviour. This in turns makes later inclusion in adult settings more difficult.

One of the major challenges facing teachers of learners with Down syndrome in the secondary school years is what to teach. By this stage, the gap between typically developing age peers and the learner with Down syndrome is widening. To decide what to teach, *follow as closely as possible what the others in the class are learning*. This has been called 'year level appropriate curriculum' (Faragher, 2014). In secondary school, learners are likely to be studying their mother tongue – Spanish, perhaps – as well as mathematics, science, history, geography, music, art, …

Sometimes teachers suggest learners are taken out of subjects they enjoy such as art in order to get extra time for 'more important' subjects such as mathematics. This is not wise. Learners need a wide range of academic subjects to form their foundations for adulthood. Also, if the enjoyable parts of schooling are taken away, the learner might lose interest in school altogether.

An equally erroneous option is to remove the difficult subjects and only offer learners simple topics or 'life skills'. The trouble with this approach is that learners are likely to miss opportunities for academic learning that are only available during the school years. Also, it is not possible to determine what learners are going to need to know years ahead in adulthood. If topics are genuinely necessary for daily living, there will be many opportunities for learning in adulthood in the context where the learning will be needed. This has been shown to be a particularly effective way of learning.

LEARNING YEAR LEVEL APPROPRIATE CURRICULUM

There are some key approaches to planning for learners with Down syndrome in the regular classroom.

1. Begin with the topic intended for the class.
2. Identify key points or concepts.
3. Focus on the assessment – how will you find out what the student knows or can do as a result of studying the topic?
4. Plan ways to modify the work to enable the learner to be included.

As an example, consider a science unit on frogs. A lesson is planned where students copy a diagram of the life cycle of a frog into their note books. The student with Down syndrome can read a little but struggles with hand writing. Vision problems make reading from the board difficult.
There is a science trolley at the back of the classroom with seedlings planted in another lesson. Someone suggests the student could water the plants while the rest of the class is completing the life cycle lesson. What should the teacher do?

Working from the principle of following what the other students are doing, the student with Down syndrome should engage with the lesson on life cycles of frogs. The important aspect of the lesson is the changes that occur from the laying of frog eggs through to the adult form. Copying the diagram is not the essential part of the lesson. Some alternative options are:

- A diagram could be provided to the student with key words missing that could be filled in.
- The stages of the life cycle could be given to the student as separate pictures. The student could then stick the pictures in the appropriate places to complete the life cycle diagram.
- The life cycle could be written as short sentences – one for each stage. The student could draw a picture to illustrate each one.

Notice how the three options above would be suitable for other learners in the class, with possibly greater learning outcomes for all.

Questioning

A surprising finding by researchers at the University of Queensland arose from research in literacy in adulthood. A small group of students with Down syndrome studying in a college program were observed by their tutor to be confused with question words such as, *who*, *where*, *when*, and *how*. They were observed to be answering the wrong question. For example, if asked 'When do you watch football' the reply was 'On TV'. It would appear that this problem is widespread, even among relatively articulate people with Down syndrome. As the authors note, this has implications

for comprehension tests which rely on questioning. It could well be that the person comprehends the material read but does not understand what information a questioner is seeking.

An implication of this research is the need to explicitly teach the meanings of question words. This can be done by using matching of the word with its meaning. For example, WHEN might be matched with a picture of a clock or the word 'time'. These words can be taught one by one. Some learners may benefit from having a sheet with question words and their meanings placed in ready view, such as on a wall above their desk or in their school workbook.

EDUCATION INTO ADULTHOOD

Most people with Down syndrome can expect to live well into their 50s. A rich education can prepare young people for a productive and fulfilling adulthood. For learners with Down syndrome, they may just be reaching their prime for learning when secondary school is over. It is important that:

- as much advantage as possible is taken to learn academic material during the school years when the student has ready access to qualified teachers
- opportunities for learning are maintained after formal schooling has finished.

School leavers may seek employment or further study. These options should be open to learners with disabilities as well. In some countries, further education in vocational colleges and also a few universities is now available in several countries such as Australia, Canada and USA (see chapter on quality of life and Down syndrome for further details). University education may seem inappropriate for learners with Down syndrome. It may be seen to be just another form of respite care that gives people something to do during the day without leading to future employment. This position was challenged by Toon Maillard, a speaker at the 'Art of Belonging' Inclusion Conference, Amsterdam, 2013. In Belgium, people with intellectual disabilities are permitted to attend university. He told of an experience of a student with an intellectual disability whose professor questioned why he was there, considering he was unlikely to get a job

afterwards. The student responded, “I don’t want a job. I just want to learn”. Higher education is the opportunity to learn and this student eloquently conveyed why this should be the right for all who wish it.

Hart and colleagues have described three approaches to tertiary education for learners with intellectual disabilities:

1. **Mixed hybrid model**
   Students attend some classes that are specifically designed for them and other general classes.
2. **Substantially separate model**
   Students attend classes and programs just for them. This might sound exclusionary but this is a typical university model. Students enrolled in a music degree would not attend classes with students in a medical course. They would likely meet at student functions, though. A similar model can be considered for people with intellectual disabilities.
3. **Inclusive individualised support model**
   Students attend general classes and receive support on an individual basis. Australia, and many other signatories to the United Nations Convention on the Rights of People with Disabilities, has laws that require the provision of supports for people with disabilities in education settings – once they are enrolled. Not all countries provide higher education as a right to people with disabilities.

Paid, open employment provides routine opportunities for continual learning and development. Often, formal training is provided to employees, such as operation of new photocopy machines. Unfortunately, in many countries opportunities for open employment are limited for people with intellectual disabilities. Sheltered employment, volunteer work or recreational pursuits may be all that is available and these often have limited opportunities for workplace learning.

Numeracy Development Plan

In situations where open employment is not available, it becomes necessary for adults with Down syndrome to take part in an explicit planning process to ensure on-going learning of topics of interest. This should include numeracy development as this has an

important bearing on a person’s quality of life (R. M. Faragher & Brown, 2006).

A numeracy development plan is a process that explicitly identifies areas of mathematics that a person would like to learn or has a need for use in the contexts of their life. More detail is given in (R. M. Faragher, 2010). The essence of the planning involves:

- Identify the contexts of a person’s life.
  One approach is to list weekly activities on a chart. Also, consider contexts a person might like to do, perhaps a new recreational activity or job.
- Select the mathematics to be taught.
  This entails making a list of all the mathematics needed in the context.
- Prioritise the list.
  The list is then ordered by working out what the person wants to learn and what is of highest priority.
- Establish who will do the teaching and where it will occur.
  Often the best place to learn is in the context where the mathematics is needed, although at times, these contexts might be too public, such as a shopping centre. Before moving to public contexts, learning in a private place, such as at home, might be more desirable.
- Plan how to teach.
  Parents and carers often make very good teachers, even though some doubt their abilities to teach mathematics. If the learning is necessary, there are likely to be people in the context who can do the teaching.

END NOTES

Education for learners with Down syndrome offers dramatic promise for pushing the boundaries of potential. Recent advances in neuroscience reinforce earlier findings that intelligence is not fixed by genetic makeup and that learning for all people is lifelong. It was once believed that intellectual development of learners with Down syndrome plateaued by the end of the teenage years. This is now known to be false. Through rich and challenging education that continues through the school years and beyond, learners with Down syndrome can achieve the most dramatic accomplishments

which would have been considered impossible only a few decades ago. If we continue to strive to expand the breadth and depth of the curriculum taught, we can only guess what will be possible for learners with Down syndrome to accomplish.

6
GETTING OLDER AND ENJOYING LATER LIFE

Karen Watchman

INTRODUCTION

As we look forward to Diego growing up and a time when life expectancy for people with Down syndrome has continued to extend, this chapter considers how far we have come in understanding how people age with Down syndrome. With an overview of the historical context, the chapter focuses on current awareness and strategies for support for both the person with Down syndrome and their parents, siblings and grandparents. How well we all age depends on a number of factors in earlier life as much as our chronological age. This lifespan approach means that everyone has a role in determining how positive an experience it is to get older with Down syndrome. The aim of this chapter is to provide guidance and information to support family and carers of older people with Down syndrome, and to aid recognition of, and preparation for, some medical and social issues commonly encountered in adulthood. In doing so the intent is to empower families to take positive action before and during the adult years.

Some of the issues highlighted in this chapter have been introduced elsewhere in the book in relation to children and young adults with Down syndrome – health, vision changes and friendships for example. However, we discuss them here alongside factors associated with ageing. This is because it is important to differentiate between conditions associated with getting older and specific issues related to Down syndrome. Unless we do so, there is an increased likelihood of missing treatable health conditions and thus impacting negatively on quality of later life.

The longer life expectancy of people with Down syndrome and associated healthy ageing is to be celebrated. My great-aunt was born with Down syndrome in the early twentieth century, and lived with her parents and siblings into her fifties. This was particularly unusual at a time when families in the UK were not encouraged to keep their children at home when born with Down syndrome. The lack of medical attention meant that the childhood

conditions we have discussed elsewhere resulted in premature deaths in childhood. Perhaps living at home with family and a meaningful role helping with younger siblings contributed to her increased quality of life, a factor we now know helps with longevity alongside routine medical interventions throughout life.

Typically, in 1983 the average life expectancy for a person with Down syndrome was 25. This has extended over the years and today for the first time we regularly see people with Down syndrome living beyond 60 years of age. As todays children get older, it will be expected that they too will reach this age and beyond. However, for the current older generation of people with Down syndrome this has been somewhat of a surprise for families who were typically told that their child would not outlive them; we now know that for many this is the reality. This leads to worry about the future when family members may no longer be able to provide care. Indeed, studies consistently show that carers are reluctant to plan ahead despite a high number of parents being over 65 years (British Institute for Learning Disabilities, 2013).

PLANNING AHEAD IN FAMILIES

As people with Down syndrome continue to outlive their parents, the role of siblings and extended family members will increase. However, siblings may lack the experience of services or support that their parents have. In some cases, this parental experience comes from decades of struggling, for example for access to services or mainstream education with parents often adopting a 'warrior' role when advocating for their child. This has often been with the backing of an intellectual disability, or Down syndrome specific, organisation. Yet, the children with Down syndrome whose families were supported in the early days of parent-led or advocacy organisations are now adults. Parents 'did their bit' when their children were younger then, using the words of many, 'took a back seat' as their child grew up, letting other younger parents pick up the mantle. Many families are now finding it difficult to step back into this role in the face of increasing health changes for their, now adult, children at a time which often coincides with their own later life and health issues.

HEALTHY AGING?

As people get older, many will present with medical conditions typically affecting older people that are unrelated to having Down syndrome. The list below suggests some health issues to be on the lookout for as someone gets older, starting with sensory changes that can affect us all. The reason for including this list is not to suggest that your family member will develop all, or even any, of these conditions as they age. However, it is important to know that each may be overshadowed by having Down syndrome which means treatable changes go undetected as they attributed to the persons intellectual disability.

Eyesight

The Royal National Institute for the Blind in the UK report that people with intellectual disabilities are ten times more likely to have serious sight problems and that Down's syndrome, Fragile X, Cerebral Palsy and Williams syndrome specifically have a direct impact on vision. Sight changes are significantly under-detected due to difficulty in separating this from the persons' intellectual disability. Examples of eye conditions associated with intellectual disability are given in table 1.

Behavioural changes or challenges that stem from failing eye sight may also be seen and wrongly attributed to Down syndrome: difficulty with bright and/or low light, hesitancy when stepping up or steps, misjudging spaces or difficulty locating food on a plate. Whilst holding items close to the face may be an obvious sign, you should also look out for new clumsiness, falling, rocking or shaking the head, increased confusion and being startled by people approaching. Some of these issues may be long-standing but any change should be investigated and it is recommended in the UK that sight be examined every two years for someone with an intellectual disability aged under 60, and annually for over 60s; alternative tests are available and some optometrists will come to the house. If someone wears glasses think about when they were last checked or how often they are cleaned.

Have a look at the images below which gives examples of how your view may be with some common sight conditions.

Imagine if you stood directly in front of someone with macular degeneration or diabetic edema. You may not be seen and would startle or alarm the person.

Eye condition	***What is it?***
Presbyopia	Age-related condition where close up focus becomes difficult
Myopia	Near-sightedness
Hyperopia	Far-sightedness
Astigmatism	Light does not focus evenly on the retina – images appear blurry and stretched out
Glaucoma	Optic nerve damage, fluid in the eye does not drain properly putting pressure on the optic nerve
Nystagmus	The eyes look involuntarily from side to side in rapid movement rather than fixing on an object or person
Strabismus	Also known as 'cross eyed', the eyes do not line up with each other when looking at an object
Cataracts	Clouded vision occurring when changes in the lens of the eye make it less transparent
Keratoconus	Coning of the cornea (it becomes a conical shape) which distorts vision resulting in multiple images and sensitivity to light (particularly common in people with Down syndrome)
Blepharitis	Chronic inflammation of the eyelid leading to irritated and itchy eyes. Typically, a long-standing chronic condition although onset and severity can vary

Table 1 Sight difficulties associated with intellectual disability.

Even if we don't realise it, most of our communication is non-verbal, whether this is touch, facial expression, mannerism or body language. A study at Princeton University in 2013 found that body language more accurately conveys emotion than just facial expression. The way we talk, walk, sit and stand all say something about us, and whatever is happening on the inside can be reflected on the outside.

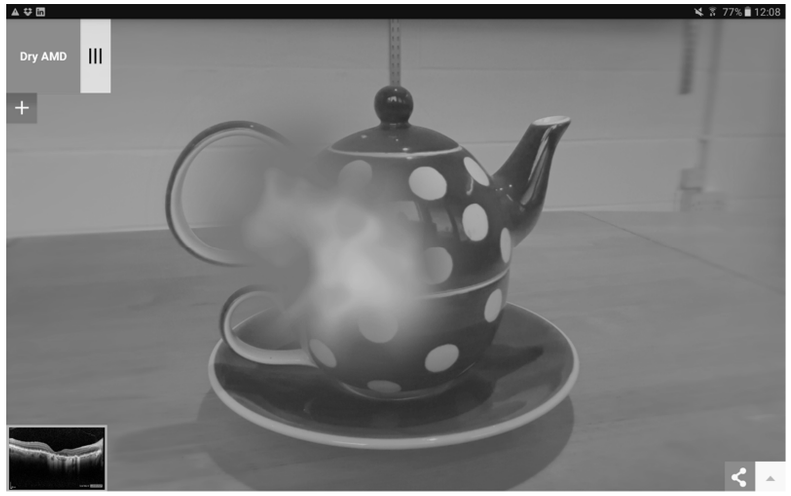


Figure 1 Macular degeneration (Watchman 2017)
Macular degeneration, which affects vision when we look at something directly. The blurred area in the centre of our vision will eventually grow larger or we will develop larger black 'floating' spots. Macular degeneration may be in one or both eyes. We may not be seen if we stand directly in front of someone with advanced macular degeneration.

Figure 2 Cataracts (Watchman 2017
Cataracts, which cause sight to become cloudy or misty. With cataracts, we may find it more difficult to see in dim or very bright light; the glare from bright lights may be dazzling or uncomfortable to look at and colours may look faded or have a yellow or brown tinge. More time is needed to adjust to a different light between rooms for example.

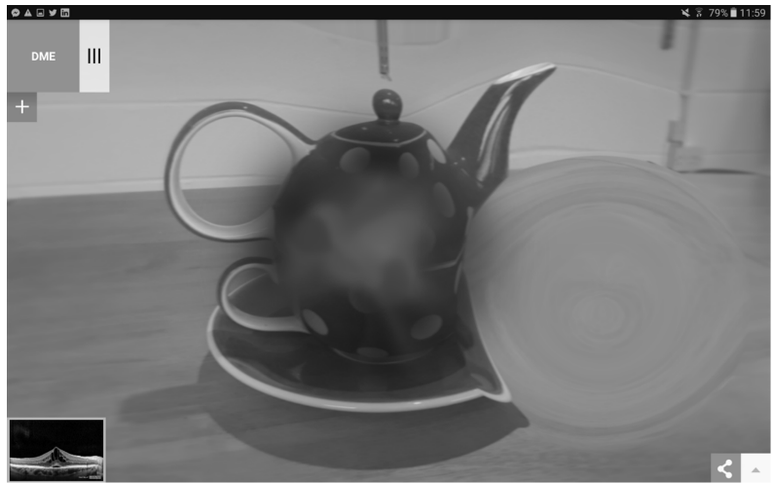


Figure 3 Diabetic edema (Watchman 2017
Diabetic edema is a complication of diabetes affecting the eye. Symptoms include blurring and distorted images, not necessarily the same in both eyes. Additionally, keratoconus especially in people with Down syndrome can result in multiple images, glare, halos or starbursts around lights and blurred vision.

We can all think of examples where we may say the right things, but in the heat of the moment our body language or tone of voice convey frustration. Provided we can be seen, standing in front of someone directly indicates attention and contact, turning away, even if continuing the conversation at the same time, indicates disengagement. The response may be to the non-verbal cues and sometimes all that will be heard is the tone of voice rather than what is actually said.

Further health and social changes that may be experienced by any of us, as we get older, including people with Down syndrome are:

- Acute confusional state, or delirium, for example caused by urine infection. The symptoms can appear as a type of dementia, but the onset and development is much quicker than dementia. An acute confusional state can be caused by poor diet, incorrect medication or doses of medication, constipation, lack of sleep or a sensory impairment.

- Side-effects of medication or a combination of medications. Use of high dose psychotropic/anti-epileptic medications

and multiple medications can contribute to further cognitive impairment. Examples may be: Chlorpromazine, Olanzapine, Clozapine, Phenobarbitone, Phenytoin, or Sodium Valproate all of which can have a sedating effect, or pain medication Meperidine and Propoxyphene which can cause confusion, or in the case of Meperidine can cause seizures.

- Typical age-related changes that we may all experience such as arthritis, osteoarthritis, tooth or gum decay, skin changes, thinning hair and height reduction due to compression of joints, spinal bones and discs.

- Effect of loss or grief. A grief reaction, for example to the death of a parent or relative, or even a long-tern carer leaving their job, can lead to changed behaviour.

In addition to these general conditions of aging we see an increased incidence of self-talking in people with Down syndrome, or private speech out loud, although this is common is often adaptive rather than a concern. This means that it is generally not associated with behavioural difficulty or social isolation. Instead it is typically viewed as a coping mechanism unless there is a drastic change in tone or frequency which should be investigated. Furthermore, an adult with Down syndrome is more likely to have physical health conditions which are not always managed well. For example:

- Hearing – small ear canals, large adenoids and small pharynx can affect swallowing making people more prone to ear infections.

- Gastrointestinal – including celiac disease, inflammatory bowel disease, reflux, constipation or diarrhoea.

- Sleep apnoea, this briefly obstructs breathing whilst asleep. These interruptions can last between 10-20 seconds and jolt the person out of a natural sleep rhythm. The incidence of sleep apnoea increases with age among people with Down's syndrome. There are three different types of sleep apnoea:

    - Obstructive sleep apnoea sees the airway blocked resulting in loud snoring.
    - Central sleep apnoea occurs when the brain does not communicate with the muscles that control breathing; it does not result in snoring.
    - Complex sleep apnoea is a combination of both of the above
- Obesity which may result in new daytime sleepiness, fatigue, napping, poor concentration or impaired attention span.
- Hypothyroidism, an underactive thyroid can lead to tiredness, weight gain and dry skin.
- Menopause, the average age to reach the menopause for women with Down syndrome is 46 years old, but it can occur up to ten years earlier than in women without Down's syndrome.

Pain

Do not assume either that your relative with Down syndrome has a high pain threshold – this is a myth and is unlikely to be the case, they may just have greater difficulty in expressing it. The discomfort and distress caused by pain is often the reason for a change in behaviour, which can lead to inappropriate use of antipsychotic medication. You will already be familiar with how your family member reacts when in pain especially if they have always communicated non-verbally – it is not uncommon for example for people to injure themselves when in pain, perhaps by hitting their head, biting themselves or rubbing themselves on the back of the arms or hands in an attempt to reduce pain. Increased or decreased head and body movements, rocking, pacing or standing still, and increased sensitivity to touch can also suggest someone is in pain (see figure 4).

Figure 4 Look out for non-verbal signs of pain (image of actor reproduced with permission from Watchman et al., 2018)

Some people may hit out or bite if in pain due to muscle spasms. Other signs include fidgeting, rocking, crying for no obvious reason, heavy breathing, knees drawn up, aggression and hitting out, night time waking, screaming or swearing.

Work in the North East of England, UK identified that family and staff carers were very skilful at identifying when the person they cared for was distressed, but often had little evidence to back this up other than just knowing that 'something was wrong'. They were also aware that pain did not always manifest itself with visible or outward signs, sometimes pain manifests itself

as silence for example. In response to this the team compiled a checklist, *DisDat* (Regnard et al 2003) to observe and identify distress cues in people whose verbal communication is severely limited. It is a resource that can be used at home and is intended to put the distress in context, recognising that although this is very individual, there are similarities between behaviour when in pain and behaviour when distressed.

Night-time pain also goes unrecognised, whether from lying too long in one position, arthritic joints, or lack of pain relief. Think about seating too – is the person sat on a chair that is too high and may be hurting their back? As we all get older our feet change shape as the tendons and ligaments lose elasticity and the arch of the foot flattens. This means we may require a different shoe size – don't assume that your family member will fit into the same shoes that they did when younger; this could be the cause of pain.

If you live with your relative who has Down syndrome it is often harder for you to spot subtle changes. Sometimes it is visiting family who have less contact, or day centre/social care staff who first notice something different. If this is broached with you by staff or family, it is always worth listening and seeking medical advice even if you have not yet noticed anything yourself.

Brain changes

A brief search on aging and Down syndrome will always bring up mention of Alzheimer's disease or another type dementia. Whilst this is incredibly scary for families it is important to be informed at a basic level so that any changes are picked up sooner rather than later. It can also help to avoid misdiagnosis of dementia which can happen, a medical change can be wrongly attributed to dementia meaning that the actual reason is not recognised or treated.

It is important to note that not everyone with Down syndrome will develop a type of dementia when they get older. For individuals who do, the impetus of this section is on stimulating discussion with and within families leading to increased confidence in providing proactive support, rather than always reacting to new situations as they arise. There remains a focus on identifying other changes associated with ageing that are often mistaken for dementia.

Why do we often hear that people with Down's syndrome experience an accelerated ageing? Although this is not well understood, it is related to chromosome 21. The extra DNA on the chromosome 21 leads to an overdevelopment of a type of protein, amyloid precursor protein, which forms plaques on the brain. Whilst we don't fully understand the function of amyloid precursor protein, we know that day to day brain activity involves a continual processing of amyloid precursor protein into shorter pieces. In doing so, one of the processing pathways produces beta-amyloid which is responsible for Alzheimer-related changes. We also know that the frontal lobes of people with Down syndrome are smaller and under developed in relation to individuals of the same age without Down syndrome; this is exacerbated with ageing.

Symptoms of changed behaviours that may indicate the onset of dementia are shown below. Whilst many are broadly similar to those seen in people without Down syndrome or other intellectual disabilities, there are some differences. The following changes are typically seen:

- Changes in personality such as becoming more stubborn or withdrawn.
- Decline in road sense or ability to travel independently
- Change in daily living skills
- Change in coordination or walking
- Increased (new) confusion
- Difficulty in stepping up or down roadsides or stairs
- Change in behaviour, reasoning or personality
- Decreased enthusiasm for usual activities
- New but persistent sadness, fearfulness or aggression

However, many of the above are also symptoms of some of the health changes we looked at in the previous pages which is why other sensory and heath conditions that we know people with Down syndrome are susceptible to should be first investigated and appropriately treated (see figure 5).

Carers, friends and family play an important part in helping to identify early changes in behaviour or personality and loss of day-to-day abilities. A baseline is a measure of someone's typical functioning; how an individual behaves and reacts when healthy. It is recommended (British Psychological Society, 2015) that baseline functioning is recorded at age 30 for people with Down syndrome. By this age the adult brain is fully developed and it is likely to be before the onset of any age-related changes. This baseline assessment should be revisited

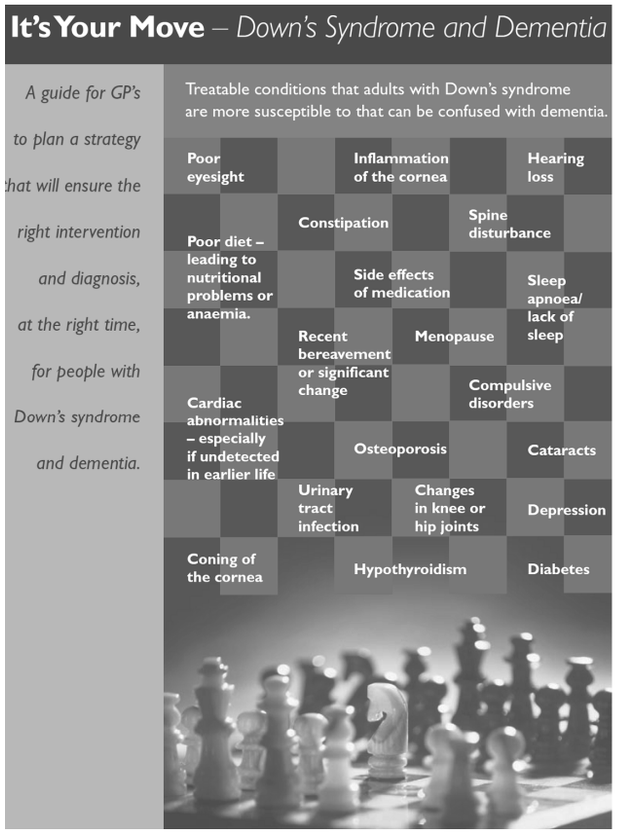


Figure 5 Guide for medical practitioners (Watchman, 2001)

every two years between the ages of 30-50 years and annually after the age of 50. An additional advantage is that this approach can help to identify many of the treatable conditions referred to earlier. This repeated baseline assessment at such regular intervals is known as prospective monitoring and is only recommended for people with Down's syndrome because of the known risk, not

other types of intellectual disability, although having a baseline of functioning will certainly be beneficial to all especially if the person is unable to verbalise health changes.

The following strategies can be tried at home to support your relative with dementia and are relatively low cost (Watchman, 2017).

- Signage can help people with dementia, even if signage has been used been used previously, don't assume that the same signs will work as the environment becomes less familiar. If it doesn't then it is worth trying something different, or re-vising in a few weeks or months.

- Reminiscence therapy, cognitive stimulation, aromatherapy, physical activity programmes examples of intervention although mostly anecdotal.

- Creating a quiet, calm environment is important but not to the extent that there is no stimulation at all for the person – the balance is ensuring appropriate stimulation for the individual. What is right for one person will be too noisy or confusing for another.

- A handrail on the stairs also in a contrasting colour can help to identify it and aid mobility

- Toilets and bathrooms can be problematic for a number of reasons – not being able to locate the on the house – signage may help, or opening the door. Signs should also be added to the inside of doors to clearly show how to exit. However, even assuming the desired room is located it still needs to be accessible. If the floor is shiny this can be viewed as water.

- Contrast is important for the person with dementia, in this example a different coloured toilet seat can highlight it. Of course, you may not want a brightly coloured toilet seat in your house – it doesn't have to be red for example or a bright colour, a black seat on a white toilet can make it more visible.

- Brighter lighting and maximising natural light

- Keeping the bathroom light on at night can help with orientation if someone gets up.
- Contrast in carpets and between rooms however may not be helpful. Look around your house, do you have differences between flooring in adjoining rooms? This can appear as a step of even a hole in the case of dark tiles or patterns (see figure 6).

Figure 6. A different colour of flooring between rooms can be seen as a step and may cause confusion

Music is known to have a positive impact on the wellbeing of people with dementia, but only if it the right kind of music and for an appropriate length of time. Think about music that you really don't like and imaging if this was played to you, even quietly, for extended periods of time. It is highly likely that it will cause you annoyance at best and agitation at worst, affecting your mood and interaction with others. It is no different for someone with Down syndrome except with complicating health factors or non-verbal communication they may not be able to tell you, or to turn it off. However, the right kind of music can be very powerful, the person may be able to sing along even if they no longer hold a conversation. Music does not place the same cognitive demands on someone and can be retained longer than speech. Even to end stage of dementia the person may retain the ability to move their hand or tap, or hum along with the music, again a different part of the brain even after the ability to sing is lost. This means that music may be enjoyed to the end of life. Unless the person expresses a preference, music or the radio should not be 'just on' for background noise.

During mealtimes, you can remind your relative to sit upright when eating to avoid coughing as much; this can lead to aspiration - when food goes down 'the wrong way'. There is also a risk of food being kept in the mouth rather than swallowing, the muscles in the mouth and throat that control swallowing don't work as well. Speech and Language Therapists can give you advice; you may be advised to thicken or puree food, after trying softer food first such as scrambled egg. If pureed, different parts of a meal should be pureed separately – not mixed together, so that the food can still be tasted.

When any health diagnosis is made it is not always helpful to 'protect' the person with Down syndrome by not talking to them about this. Often, just as with all of us, the person may well be aware that something is wrong and may indeed be reassured to have confirmation of this and that they can be helped. Taking this rights-based approach, someone with Down syndrome is entitled to be told of their diagnosis. We have heard arguments against sharing a health diagnosis more than for. Typically, '*he wouldn't understand*' or '*I don't want to upset her'* are the two most

common reasons given which are understandable. However, this doesn't make the health diagnosis or its implications go away.

Colleagues and I developed some guiding principles and strategies to break down information if you have concerns over how much information will be retained or understood:

- What information would help explain that s/he is ill?
- How much information would help him/her today?
- How will I convey this information?
- What information do other people need today so that we are all consistent?

This removes the need for sharing a health diagnosis or a significant change as a one-off activity and instead presents it as an ongoing process that is centred around the person with Down syndrome. It recognises that the actual diagnosis such as 'cancer' or 'dementia' may not be understood, in which case it will not be helpful to use the words, and it also acknowledges the involvement of others who provide support, both professionals and friends or a partner with intellectual disabilities. We will consider how the way in which we communicate can lead to misunderstanding or confusion before looking in more detail at the guiding principles for sharing a health diagnosis with a relative who has intellectual disabilities.

SHARING A HEALTH DIAGNOSIS

The 4-staged model (Watchman et al, 2015) below suggests a framework to use when planning what to say.

Life story work can help to build up a picture of current understanding and of past experiences, significant relationships and previous changes or losses experienced. New information will only make sense if it fits within someone's framework of knowledge – their background knowledge, what they think is happening now and what they think will happen in the future which may be incorrect.

Life story work stems from work with children who were about to be adopted and now supports children or adults to recognise their

1. Find out the persons current understanding about their past, present and future
2. Decide which small pieces of information are needed today and the appropriate format
3. Give one pieces of information one at a time in relation to parents understanding
4. Check and revisit understanding regularly – this will change and the words used may need to change accordingly

Figure 7 A stepped model for sharing information about health (Watchman et al., 2015)

past, present and future. However, this work has often been started much earlier with people who have an intellectual disability; be aware that life story work is not always positive and may recall distressing memories.

WHAT DO PEOPLE WITH DOWN SYNDROME WANT AS THEY GET OLDER?

If we were to answer this honestly it is likely that we would say we really don't know, because we tend not to ask. Many people with Down syndrome will not see themselves as getting older and the concept of 'retirement' is a difficult one. This is not surprising given that daytime activity, whether voluntary or paid employment, also provides a significant social interaction for many people with Down syndrome. It also highlights how far many people with Down syndrome rely others to facilitate social engagement or activities as this stops suddenly after individuals retire from day services, if this is the norm for their services. Typically, on retirement an older person (without Down syndrome) will engage in more leisure activities or take more holidays. We must support people with Down syndrome to ensure choices are available as they age in order to maximise wellbeing.

Typically, people with Down syndrome are sociable however some adjustments with lifestyles or with housing may be needed with aging. It is important to continue activities that are

enjoyable, even if extra help is needed such as with transport. Boredom especially may lead to negative behaviour or depression whereas wellbeing can be improved by activities and relationships that are important to the person. As people with Down syndrome age, so too will their parents – often siblings or other family members will take on more of a caring role however it is still important that as a family there are proactive plans made (Foundation for People with Learning Disabilities, 2015). This is to avoid a crisis situation typically caused by illness or disability of older family members. Should a change in accommodation be required then the more time spent planning this the better. Ideally any move will still involve close proximity to family and friends. If the change is a temporary move to hospital, then it is important that nursing and health professional understand how best to communicate. Often it is family members who best provide this communication link but if families cannot always be there, then likes, dislikes etc should be shared amongst all who provide care.

Abilities and capabilities	Environment and activities	Conditions	Resources
• Physical • Psychological /behavioral • Cognitive • Functional abilities (activities of daily living) • Sensory (vision, hearing, touch, smell) • Communication	• Living arrangement • Employment & retirement • Social engagement / activities • Day program activity • Daily Routines • Spiritual Support • Likes / Dislikes • Safety Risks	• Nutrition • Oral / Dental • Elimination pattern • Sleep pattern • Medical conditions • Allergies & intolerances • Medications • Prevention care • Treatment & services • Palliative & end of life care needs	• Community services & support • Funding • Staffing requirements • Transportation needs • Legal

Figure 8 Topics to consider in care coordination (National Down Syndrome Society, 2013)

Regardless of the place called ‘home’ and whether temporary or permanent, the National Down Syndrome Society

identified the following domains (see figure 8) of the persons abilities, environment, challenges, preferences and resources to be considered when providing comprehensive care as a person gets older with Down syndrome.

Increasingly around the world, we see adults with Down syndrome breaking free of stereotypes and challenging perceptions. From Madeline Stewart and Katie Meade, models; Oliver Hellowell, photographer; Chris Burke, Pascal Duquenne, Sarah Gordy, Sanna Sepponen, actors; Karen Gaffney, sculptor; Angela Bachiller, politician; to Isabelle Springmühl, fashion designer, we are seeing a new generation of role models who have Down syndrome and who are blazing a trail for Diego and other children to follow in the future.

Part Two

WHAT LIES BENEATH DOWN SYNDROME

Down syndrome is an alteration of genetic information. Human beings have 23 pairs of chromosomes: each one of them is like a chapter of a book known as genome. In it there is the information required for the development of the being as well as the history of its ancestors dating to thousands, possibly millions of years.

For reasons not entirely known a person with Down syndrome has duplicate sections on chapter 21, which is the cause of both physical and mental traits. It must be said that such alteration has nothing to do with inheritance and is made of perfectly healthy genetic material; there is merely repeated information.

In the chapter on genetics it is described how in the evolution of the Universe the necessary information is generated so that they can be replicated from the simplest elements to the current complex forms, both mineral and alive. A consequence of this path is the enormous diversity in human beings, one of whose cases is that of those with Down syndrome.

At the beginning of the twentieth century, people with Down syndrome had a life expectancy of 11 years; currently it is more than 55 and it is not uncommon for some to live more than 70. This is largely due to the development of health practices (Wright, 2011; Brown et al., in press) that have relied on advances in genetics.

In the countries with more development, health surveillance for people with Down syndrome is very strict. To detect problems in a timely manner, the pediatrician first reviews the baby's general condition; when it determines that there is some risk, it is channeled to the clinics that handle the different specialties. For example, just over a third of babies with Down syndrome have a problem with their heart and in some (not all) of them the problem can be serious. Possibly this was one of the causes of the belief that babies with Down syndrome would live a few years. The chapter on health describes the most frequent disorders that can occur in a person with Down syndrome not because they are usually given in all cases but because it is important to know them to prevent them

7

SOMETHING ON GENETICS

Manuel I. Guerrero

Down syndrome is a natural condition, a result of thousands of millions of years of evolution

FERNANDO DEL RÍO

INTRODUCTION

Down syndrome cannot be fully understood without discussing genetics; the trouble is that this is a tricky subject: it requires a good knowledge of chemistry, biochemistry and physics amongst other sciences. Going deep is far beyond the scope of this book, but many people are exposed to Down syndrome by the statement

> *"Is a genetic disorder caused by an additional chromosome in pair 21 and that extra chromosome means a disturbance in infantile development".*

So we felt necessary to clarify these concepts, although superficially. For that we need to know what a chromosome is, how evolution became to reset the transmission of information for particular entities and their role on the physical and intellectual characteristics of living beings. Our aim is to explain scientifically the above mysterious statement.

To appreciate the beauty of evolution, from the beginning of the Universe to the appearance of life, would help readers to understand the almost unbelievable complexity of what we are. Life is based on a chemical element (carbon) whose existence dates from the first times of the Universe but it is due to an improbable event that is life had its origins in a possible but highly unlikely event.

Carbon associated with other chemical compounds to give rise to self-replicating molecules that is they possessed a primitive way to transmit information, which is one of the characteristics of a living organism. Later evolution, due to mutations (spontaneous genetic changes) some positive but some others negative, reached a

stage pf sexual reproduction which increased viability, and thus the possibilities of primitive organisms to adapt to changing environments was improved – a sort of natural selection at the microscopic level.

To understand all the above we shall see the role of chromosomes in transmitting information from parents to their offspring. But evolution is so complex that not everything rests on mutations. Sometimes the development plan of a living being is altered by the spontaneous appearance of a chromosome in a place it should not be. This is healthy genetic material but in the "wrong" place, and that "confuses" the plan. This is known as a trisomy and may happen in each of the 23 pairs that make up the human genetic information. Down syndrome happens when the chromosome goes with 21st pair. In spite of being made of normal genetic material. The trisomy provokes undesirable effects which fortunately are now in many ways reduced through medicine and education.

Two final words: we also hope to make clear that Down syndrome does not depend on anything else than a spontaneous modification in the development plan of life. It cannot be ascribed to heredity (except in a rare case) or behaviour of parents; what we would like to emphasise is that there is no room for guilt. And the second: for the future there is research towards obtaining a solution to the changes Ds causes. Such research is still in its very incipient stages and a number of unforeseen obstacles or challenges are likely to appear. Are we on the right track? Yes, but it would be irresponsible to say that a "genetic cure" is at hand.

LIFE

Life is amazingly diverse, in its presence, its stability, its adaptability. In the most inhospitable places there are signs of it, in the depth of the oceans, in the eternal snows, on the top of the highest mountains and in the driest deserts, not speaking of woods and forests where variety seems infinite. Yet its diversity and complexity make difficult to believe that its origin so distant in time was as humble as the two first elements in the table of the elements (see below). This is an amazing story that begins with the Universe itself, full of moments where it seemed that it was coming to an end, improbable but possible circumstances, almost

total extinctions putting life to an extreme test over which evolution has come victorious.

There seems to be a well defined direction in time: each geological era has had its own characteristics that fostered the prevalent forms of life, and would be poisonous for life belonging to other era. If we might bring to the present a form of proto-life it would be immediately eliminated.

Many species who lived on Earth have vanished, or have evolved into others. Stability of life rests upon its capacity to change, to explore new forms, and within each there are subtle changes – mutations – that help to improve the chances of survival.

The purpose of narrating this story is to invite the reader to appreciate the wonder of this phenomenon that we call life so common that we take for granted, and yet … it almost did not happen.

In order to have a glimpse at the origin of life we must go back 14 thousand million years, three times the age of our Earth to see how the Universe was at its beginnings. What follows is speculative, but consistent with the present scientific knowledge.

THE ORIGIN OF THE UNIVERSE

It is commonly accepted that the Universe began with an incredible big explosion, the so called 'Big Bang'. In this primordial chaos there were only particles colliding with each other at such enormous speeds that it was impossible for them to bind together since their energy far surpassed the one required to do so. That was a soup of indistinguishable matter and energy. Temperature was 100,000 million kelvins or about 6,400 times that of the centre of our Sun, and density was 234 million times that of it. A mass the size of Mount Everest with that density would destroy instantaneously the Earth by a gravitational collapse. What existed before the Big Bang belongs more to philosophy than science and it is of no interest for the present discussion.

In a very short time, three minutes and forty-six seconds the primeval soup expanded rapidly, cooled down, became orderly and the path of evolution was clearly established (Weinberg, 1977). The Universe began to expand and cool down quickly. Only 0.11 seconds had elapsed and temperature was already a third of the initial, but still too high so nothing changed qualitatively.

When the Universe was 13.82 seconds of age, temperature had descended to 3,000 million kelvins, below the threshold where nuclei may have a stable form although the rapid expansion made them acquire different configurations: helium (He) formed in a light form and hydrogen (H) in a heavy form. A chemical element is defined by the number of positive particles existing in its nucleus (or protons): one for hydrogen, two for helium and so on as shown in the figure, called the periodic table of elements*. These positive particles are balanced by neutral ones (or neutrons), the sum of the two gives the mass of the nuclei: one for hydrogen (no neutrons), four for helium. The "abnormal" elements in the early times were a light helium (two protons, only one neutron) and heavy hydrogen (one proton and two neutrons). These particles are not tightly bound and easily decompose.

After three minutes and 46 seconds the Universe was full of stable nuclei of helium and hydrogen and from there they began to react one with the other to form heavier nuclei. The next one in the table of elements is lithium (Li) formed by the fusion of a hydrogen and a helium (1+2=3) and denoted lithium-6 (6 for its mass).

And then problems began. The fourth element, beryllium (Be) needs two helium atoms to fuse together (2+2=4), but this gives a very unstable configuration which decays extremely rapid into its two constituent nuclei. Life depends on carbon (C) the sixth on the table below which may be formed by a beryllium nuclei fusing with helium, but if beryllium is so unstable there was little chance for it to be formed. However carbon exists, so there must had been a mechanism for it to be formed, however unlikely to happen. That mechanism was predicted by Fred Hoyle in 1954 and confirmed experimentally three years later, yet the mechanism was poorly understood (Jenkins and Kirsenbom, 2013). Recent research by a team of Mexican, British and American scientists (Marín-Lámbarri et al., 2014) confirmed that to the two nuclei of helium that forms beriluim-8 a third helium is incorporated forming a triangle that although extremely short-lived gives way to

* Strictly speaking a chemical element is a nucleus surrounded by a cloud of electrically-charged particles known as electrons, and those electrons are responsible of binding together atoms into molecules, but details may be found in any elementary chemistry book and we do not wish to distract the reader.

an unstable form of carbon that by emitting radiation forms carbon-12, which is stable. Life in the Universe began with a possible but extremely unlikely event, a subtlety in the nuclear structure of helium.

Later on heavier elements began to form and which were to be parts of the life molecules: nitrogen (N) and oxygen (O), occupying the seventh and eight positions in the periodic table.

Of course this did not happen suddenly, but took millions of years. Life began slowly to open its way in a simplicity that is extremely elegant. This is the beginning of the evolution of the Universe … and the evolution of Life.

CARBON AND THE FORMATION OF LIFE

Carbon is an element different to the rest on account of its exceptional ability to associate with others, and invariably is present in every life form. All organic molecules in living organisms have at least carbon, hydrogen, oxygen and nitrogen.

The next step in our story is the formation of aggregates of chemical elements, known as molecules. So somewhere in time a nitrogen associated with two hydrogens to form an amine and a carbon, two oxygens and a hydrogen formed a carboxylic acid. Those two elements are the constituents of the first brick of life, an aminoacid.

The formation of aminoacids requires conditions presently non-existent on Earth but apparently common in the early times when our planet began to form. What would happen if these conditions were replicated today? Aminoacids are synthesised. Such a process was theoretically proposed by the Russian scientist Alexander Oparin (Oparin 1952) and independently by the British scientist, John Haldane and experimentally demonstrated by Stanley Miller and Harold Urey from the University of Chicago. This is a great story. Miller was a doctoral student of Urey, and he wished to do his thesis in this subject. Urey was hesitant but

agreed to give it a try, for a short time. Once they had the experiment set, Urey had to do a lecture tour, and advised Miller not to begin the experiment without him, but Miller was an impetuous young student and did it … and aminoacids were formed! As a form of reprimand, Urey forced his disobedient student to present his results to the full faculty … and received an ovation (Lazcano 2010).

When Charles Darwin proposed his theory of evolution (Estrada and Lopez-Beltrán, 2009) he considered the mechanism of natural selection to explain the evolution of species accounted for the existing life, but he avoided to enter in the question of the origin of it, at most he assumed there should have been a "small hot pond" where life originated.

Another problem Darwin left aside was the stability of the variability. If, as he discussed, descendents have a mixture of the characteristics of their parents soon variability would decline, something contrary to observation. The answer is that characteristics of parents *recombine*, more than being mixed, as the Austrian monk and scientist Gregor Mendel discovered in his simple yet profound observations. Unfortunately his writings found their way to the dusty cellars of his monastery waiting to be discovered and appreciated in the 20th century.

Summarising, in its almost four minutes of existence, the Universe passed from a chaos where matter and radiation were indistinguishable to an order which gave rise to the first two chemical elements. Inorganic matter evolved. After a long time carbon and heavier elements formed aggregates due to propensity of carbon to associate with other atoms. That led to the first amino acids, combinations of hydrogen, carbon, nitrogen and oxygen which have the capacity to associate in more than 500 different forms, giving rise to complex molecules such as proteins. In the

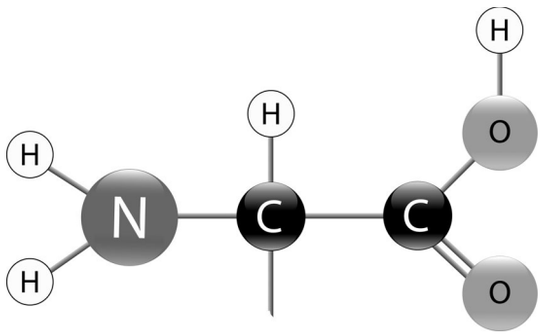


figure a schematic form of an aminoacid is shown, the free "link" in the bottom forms the bond with other molecules.

Where does the information reside?

So far what we have said about the origins of life is incomplete, though what we have come to understand is based upon rigorous scientific principles. Once the first molecules began to exist they became more and more complex until at some moment (impossible to say when) deoxyribonucleic acid, DNA, began to exist. This is the molecule that contains the information for every living form, including viruses, since it has the extraordinary property to "replicate" itself, which is when it splits longitudinally in the process of cellular division to join a similar molecule that splits also giving way to two cellules carrying the same information. DNA is thus a manifestation of life.

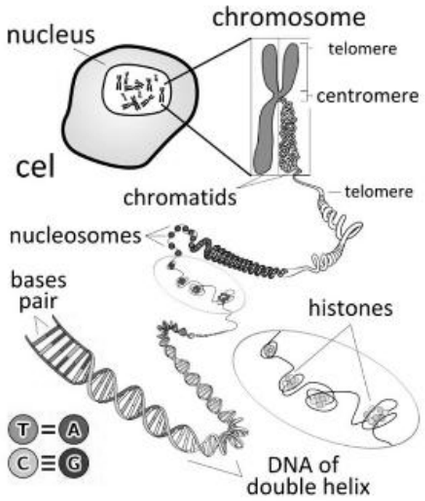
The DNA molecule contains the signals sent to every cell to perform the function it is expected from it in order for an organism to grow and thrive, but it contains as well the information inherited from ancestors and transmitted to descendants. This means that DNA is not only a book of instructions but of history also containing the information necessary for an organism to work and the information of the genealogic tree. And being so important this molecule is kept within the nucleus of the cell and whenever information is needed a messenger is employed to transmit it to proteins, which are the molecules that make cells act. The messenger is known as ribonucleic acid, or RNA.

The full set of genetic information (blueprints and history) is called genome and comprises DNA, RNA and some proteins. Genome is organised in structures known as chromosomes each of which contains segments of DNA known as genes together with all necessary instructions to make them act: interaction signals, RNA and proteins. Interaction signals to combine genes constitute 98% of a DNA molecule.

Every living being preserves its information in chromosomes: microorganism have only one, humans have 23 pairs, 46 chromosomes in total. Of them 22 govern development of the person (numbered from 1 to 22) and the third pair determines gender and they may be X or Y. If the pair is XX the person will become a female, if XY will be a male. Oddly enough

the probability for a male is 51% and for a female 49 % When the first living unicellular organisms began to exist they already had an awesome complexity in their genomes, all the history of evolution up to their creation plus the fundamentals for the evolutionary process to proceed. This was demonstrated when some non-functional genes were discovered and were named pseudo genes. They are remains of extinct species. For example, all mammals except higher primates are able to synthesise vitamin C which probably happened when our ancestors began eating fruits and thus the need for vitamin C synthesis disappeared. In human beings there is a pseudo gene whose function suppresses the synthesis of vitamin C; there are genes related to the capacity to digest large volumes of vegetation, with the existence of a tail or a sagittal crest.

The work of the genome is manifested through inherited traits. For example this is shown in the colour of eyes, body



complexion and even some behaviour tendencies, although it is not as simple as a gene for blue eyes and another for dark skin. In fact genes are team players and seldom act individually, so an important part of genetic information is precisely that, the one that tells genes how to combine for a specific task. Besides the environment also influences these interactions and may cause stable changes that may be not only inheritable but transmitted to the third generation, an example of this is damage caused by

tobacco smoking (Breitling et al. 2011). Another example is famine which brings severe consequences to future generations.

DNA is a very long molecule, in the order of metres. How does it fit in a tiny space of the order of fractions of a millimetre? The only way is to twist and compact while preserving its integrity in such a way that information is easily retrieved when replication takes place. The way nature has done it is through successive foldings first around a molecule acting as a spool (known as histones – see figure*) and later on in the chromosomes.

In all sexually reproduced organisms – happening in bacteria as well as in humans – the new organism has the genetic information of both parents. In each of the cells of a human being there are the 46 chromosomes coming from two very special cells, the ovum and the spermatozoid, generically known as gametes, and are characterized by having only half of the number of chromosomes from each parent. Those chromosomes are similar but not identical, and have their genes located in the same positions in a similar but not identical manner.

Evolution resulted in sexual reproduction because it has the most survival value and helps to control malign characteristics from one or both parents and also is the best way to adapt to changes in the environment. An example of damage control can be seen in the so called sickle cell disease; in this case information is corrupted giving way to deformed red cells which flow with more difficulty leading to anaemia, general weakness, lack of air and cardiovascular problems (Barahona & Piñeiro 1994 : Soberón 2005). If both parents are carriers of the disease – the worst case – their progeny have a chance of 1 in 4 to have the disease, 1 in 4 of not having it and 2 in 4 of being carriers. In this way the disease is eventually controlled statistically i.e. not every one will inherit the condition. The condition in this instance is called recessive.

Descendants from two different families have a combination of characteristics from each of them. Why different? Because genes are similar but not identical; each gene has slight changes called mutations (from Latin, *mutare*, change) and

* Figure taken from "Graphic decomposition of a chromosome (found in the cell nucleus), to the bases pair of the DNA". This file is licensed under the Creative Commons Attribution 3.0 Unported license. No changes were made. See https://commons.wikimedia.org/wiki/File:Chromosome_en.svg

happens spontaneously all the time. A set of genes that are similar, or alternative, is known as allele (from Greek *allelon* – one to another). For example blood types arise from alleles and so does hair colour. One dominates over the other (dominant and recessive), and so a blond mother and a brown-hair father may give rise to a brown-hair child but in turn in a following generation blond hair reappears. So alleles manifest as traits, and the set of traits is known as phenotype, and it is on this that natural selection acts, and is consistent with the work of Darwin and Mendel. (Piñeiro in Estrada and López-Beltrán (editors) 2009)

A genotype refers to the genetic makeup contained in all alleles in a cell, an organism or an individual. A good way to understand phenotypes and genotypes is to relate them in the different blood types.

Classical genetics recognises three different blood alleles, I^A, I^B, and I^O, that determine compatibility. Any individual has one of six possible genotypes (AA, AO, BB, BO, AB, and OO) that produce one of four possible phenotypes: "A" (produced by the combination of AA and AO), "B" (produced by BB and BO), "AB" (which is AB), and "O" (which is OO) and those are the so-called blood groups. Recent studies have shown more intervening alleles, but the principle is the same.

So, sexual reproduction means that starting with two parents their descendents exhibit variations, which may bring along problems (such as negative Rhesus factor high blood pressure or cardiac issues) but also improvements are made through natural selection over time

This is also heritability, part of it comes from genetics but partly by the environment (natural selection acts to adapt in the best way to it, i.e., survival of the fittest) that plays an important role in terms of genetic effects. Heritability on its own tells little about individuals but provides an estimate of the variations that occur within populations. All there is are probabilities of events taking place.

Environment acts also upon natural selection. Such is the case of the synthesis of vitamin C referred above, since for early higher primates it was presumably easier to take it from outside (i.e. from vegetation) than synthesise it. However most variations caused by environment such as the colour of skin have no great

impact on overall genetic makeup. All humans have in common 99.9% of genetic makeup. Even with extinct species such as Neanderthals, common genetic makeup is as high as 99.5%.

TRISOMY

Until now we have seen alterations in the flow of information due to mutations (which are spontaneous and happen all the time) that give rise to the alleles. Mutations have been accumulating through the history of our species and as Darwin rightly pointed out have to do with natural selection (not at the gene level but at the trait). For example almost all mammals except primates can make their own vitamin C; why can't we? In simple terms because sometime our ancestors chose eating fruit and so the synthesis of vitamin C was no longer necessary. This is adaptation to the environment, but we need to eat fruits otherwise we may be in trouble.

Information can be lost by natural causes or may be induced, for example by smoking (Breitling, 2011). Such information when transcribed produces altered proteins and the effects may last for at least two generations.

There is another way for the information to be altered. In this case there is no external cause nor is a mutation involved. This is known as a Trisomy.

To understand this, it is necessary to go back to the formation of the sexual cells, the spermatozoid and the ovum (both generically called gametes). Since the fertilised ovum must have 46 chromosomes, each gamete has only 23. The formation of them is a special process known as meiosis during which chromosomes recombine randomly, that is each one is different to the other sperm or ovum: that is why siblings although sharing many traits are not identical (identical twins are a special case, yet they are not carbon copy of each other). Obviously traits are inherited, but slightly different genes (alleles) yield different phenotypes – remember every human being shares 99.9% of their genes – and a mere 0.01% makes every being unique since the number of combinations are thousands of millions.

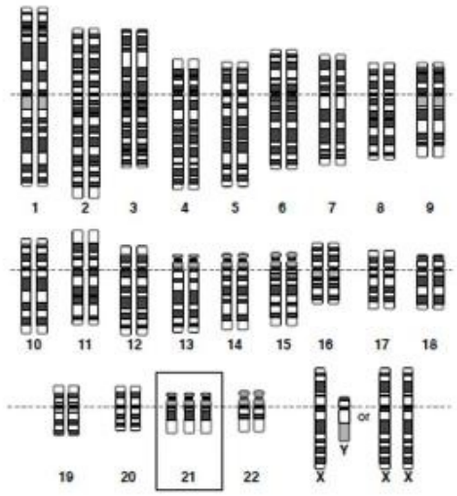


Fig 4 Trisomy on chromosome 21 ICourtesy of the National HumanGenome Research Institute)

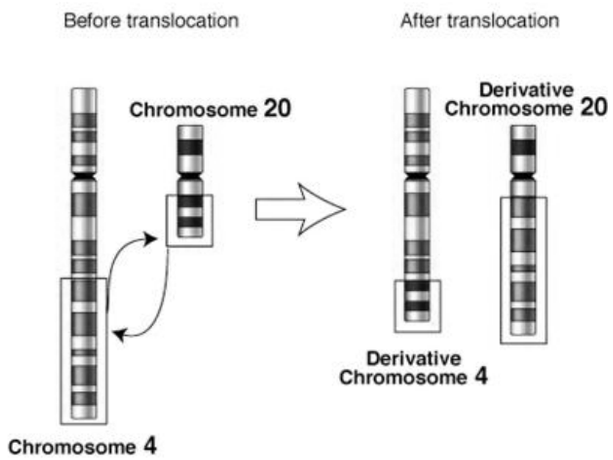


Fig 5. Translocation in chromosomes 4 and 20

Well, it may happen that during the formation of gametes (the sperm and egg) some chromosomes fail to separate completely or do not separate at all. This is a Trisomy (from three) and may happen in any of the 23 pairs, though with very different effects. It even may happen as a more complex phenomenon, a rearrangement of chromosomes, say material from chromosome 4

inserts in chromosome 20. This is known as translocation, for "changing places", and happens in cancer as well as other situations. Translocation may be balanced, meaning when for example chromosome 14 goes to join a 21 and vice verse, but this is a rare case.

Trisomy may be full or partial, depending if there is a whole chromosome duplicated or just part of it, and may also happen after fertilisation, in which case some of the daughter cells will have extra genetic material (47 chromosomes) but others not.

The most common Trisomy is 16 and happens in about 1% of pregnancies, although normally ends in a spontaneous termination of pregnancy. The other frequent trisomies are 21 and 18; as we said there may be in any chromosome, but they are incompatible with life and a spontaneous termination of the pregnancy results.

Down syndrome results from Trisomy 21, which was first interpreted by the French geneticist Jérôme Jean Louis Marie Lejeune in 1958 and communicated before the French Academy of Sciences the following year. Lejeune was studying the causes of Down syndrome since the early 50's with the techniques available at that time, mostly phenomenological. When a new tissue culture technique developed in the United States was brought to his attention, he was able to conclude that the root of it was in the existence of an additional chromosome which we know now produces an overabundance of chemical signals, causing functional imbalances throughout the body. Until then, the laws of human heredity had been unable to explain Trisomy 21 and other anomalies in hereditary material.

When Trisomy 21 arises after fertilisation and some daughter cells have extra genetic material while others not, a case of mosaicism is produced, that is there are cells with different genotypes. There is debate whether this particular condition results in lesser restriction of intellectual ability (Cunningham 2006; De A. Moreira et al. 2000). Mosaicism happens in about 1% of persons with Down syndrome.

As we have seen genes are team players, amongst them and with the environment. The overabundance of chemical signals due to the extra genetic material will certainly have effects, no doubt about that, but to what extent is not yet possible to predict.

There are, however, certain conditions which very likely will be present in persons with Down syndrome as discussed on chapter VII, physical characteristics and health issues.

GENETIC ENGINEERING

Humans have been modifying Nature since the early days of civilisation. Domestic animals were obtained by selecting breeding of wild species; the dog is an outstanding example: it does not exist in the wild, it is a genetic modification of the wolf. Agricultural species were also tamed, such as cereals and fruits.

Presently bone marrow is transplanted to correct some diseases, in a more modern way of genetic manipulation.

With the advances in molecular genetics some daring modifications are being done. It is possible to genetically modify new *E. choli* bacteria by inserting segments of human DNA to produce human insulin which has the advantage of not having compatibility issues that in the past caused so much pain to patients with diabetes. There is serious talk of making personalised genetic cures for cancer and other diseases, which would attack only malignant cells. However at present this has been carried out with limited success only in lower vertebrates, or in vitro for single cells. It seems indeed a promising path, but still a long way to go for a clinical practice. A true scientist should always be careful in order not to give rise to unfounded expectations, yet maintaining an open mind.

IS IT MEANINGFUL TO SPEAK ABOUT A "GENETIC CURE"?

Many have asked about the possibility of a "genetic cure" to Down syndrome. A few years ago the answer would have been a qualified no, for a number of reasons:

First of all Down syndrome is not a disease but a condition arising from a combination of perfectly normal genetic material giving way to an overabundance of chemical signals – a sort of two traffic lights both in green: drivers would not know what to do. Had at least one of them been abnormal a correction would have made more sense;

Secondly it seemed difficult to visualise how a genetic intervention could "silence" some of those signals, and their implications, for

example in the production of proteins (or the lack of them). Until recently this idea of silencing the effects of a whole chromosome appeared beyond the realms of possibility, even in the laboratory.

It seemed more a matter for health and social sciences, aided by the genetics knowledge, to inquire where the root causes of the main disorders were and how to prevent further problems, such as the relation between a malfunctioning thyroid gland with over or under behavioural activity. That was about the extent of solutions genetics could provide at the time, and for practical reasons social sciences and education were the only ways potentially available to provide better quality of life for instance by studying the learning process and devising ways to facilitate it.

But research in the early 2000's threw new light on the relation between some severe learning defects and biochemical disturbances. Apparently when a gene located on chromosome 21 was "silenced" some of those disturbances tended to disappear and since the problem was not with the brain itself, once the signal was suppressed the learning defects disappeared. Being so, a cure could be pictured mentally, not as an immediate fact but as a distinct possibility.

There is a fruit fly (Drosophila), which is a popular experimental animal because it is easily cultured in mass, has a short generation time, and mutant animals are readily obtainable. In this fly chromosomes were identified by Thomas Hunt Morgan as the vector of inheritance for genes for which he received the 1933 Nobel Prize in Medicine. Since then some have been referring to Drosophila as "human beings with wings" since they have many similarities to humans not only in the genetic side but also in their behaviour. Did you know that Drosophila show a aggressive behaviour when they are drunk before passing out! They also may be mutated to exhibit some human conditions, such as Down syndrome, so fruit flies are a good research subjects to test hypothesis[*].

[*] The correlation between flies and mice with humans is possible because there is an interesting evolutionary fact: early studies of evolutionary relationships among groups of species and populations demonstrated that the sequences of some molecules were conserved in different organisms including, mammals, amphibians, birds, reptiles, sea squirts, and sea lampreys.

In 2003, a research team of the Neurogenetics Branch of the National Institute of Neurological Disorders and Stroke in Bethesda Maryland (Chang et al. 2003) generated a population of fruit flies which exhibited severe learning defects, attributed to biochemical imbalances rather than misdevelopment of their brains. Learning impairment was due to those deviations and there was nothing wrong with the brain. These results, combined with previous data, strongly suggested that the same could be happening in humans leading to mental retardation in Down syndrome.

Later studies with mouse models of Trisomy 21 suggested a link between characteristic phenotypic changes and increased activity of specific genes, which may allow an understanding of the molecular basis for it. If so, it seemed possible to understand and to effectively treat the most distressing symptoms and signs of Down syndrome.

For example, an over expression of a particular gene might be harmful to DNA synthesis and repair; others may cause heart defects, and a third one might contribute to the development of cataracts (Mégarbané et al. 2009). The causes of leukaemia and skeletal abnormalities were also ascribed to certain genes, however it must be emphasized those studies were done in animals mimicking the behaviour of humans, not in humans themselves. Recent data from functional neuroimaging studies support the promise for the development of treatments for intellectual disability (Dierssen 2012).

A group from the Department of Cell and Developmental Biology of the University of Massachusetts tested the concept that gene imbalance can be corrected by manipulating a single gene using a technique for "coating" a whole chromosome 21, that is silencing it, using some kind of methylation, which is the process that occurs with smoking that was described above. This technique seems to surmount the major first step towards potential development of chromosome therapy by eliminating some of the extra chemical signals (Jun Jiang et al. 2013).

Work at Sanford-Burnham Medical Research Institute has gone in the direction of natural protective mechanisms against viruses to investigate therapies for diseases such as cancer, diabetes, cardiovascular diseases and genetic disorders (Xionga et al. 2013). This natural defence is contained in a small component of RNA

(the DNA messenger molecule) encoded in a gene whose acting results are inhibiting malignant growth, viral infections, and attenuate the progression of cardiovascular diseases and is known as miR-155.

Armed with this information, the Sanford-Burnham scientists asked themselves why the extra chromosome 21 alters brain and body development. Apparently the production of a protein which is necessary for proper brain functioning is inhibited by miR-155 encoded on chromosome 21. The extra copy of chromosome 21 means a person with Down syndrome produces an excess of miR-155 which signifies a decrease of the protein, so the lack of it is at least partly to blame for developmental and cognitive defects, so mechanisms of learning, memory, and behaviour are impaired. The amazing fact is that by removing the excess of miR-155 everything goes back to normal, the memory deficit is repaired.

If that is so in mice, could it be accomplished in people with Down syndrome? The researchers say that "Gene therapy of this sort has not really panned out in humans, however. So we are now screening small molecules to look for some that might increase protein production or function in the brain." Work is in progress and results are encouraging.

However there is a huge step between these experiments and an actual practice in humans. The technique seems promising, but experience has demonstrated over and over again that solutions that seemed within reach hide enormous difficulties in practice.

True awesome advances have been made in the genetic cure of diseases, but they are precisely that, diseases. Down syndrome being a result of perfectly normal genetic material but combined in such a way that disrupts the functioning of the body is a more difficult form of problem to alter it genetically. Is it possible? It seems that the answer is yes, but still there a long way to go.

It would be irresponsible to speak with the present knowledge of a cure being available in a definite time span. What we know however provides practical answers particularly in being aware of potential problems – in health and behaviour – and seeks answers to them. Medicine, psychology and education applied together can lead to a high quality of life for people with Ds. Once preconceived ideas have been set aside (for example the belief that

people with Down syndrome cannot learn to read) new avenues for development are opened.

Finally, something worth mentioning because of its frequent misunderstanding among lay people is stem cell therapy. This is indeed an active and promising field of research on which there are many hopes founded. Scientists are investigating regenerative medicines and using them for liver regeneration and fibrosis, for haemophilia (the hereditary bleeding disorder), and to repair heart damage or mend a broken bone. They are also used to treat cancer-related malignancies (leukaemia, lymphoma, myelomas, etc.), anaemia, metabolic disorders, viral diseases, amongst others. The most common and firstly used stem cell therapy was the transplantation cells usually derived from bone marrow.

Stem cells have the remarkable property of repairing or replacing tissue damaged from disease or injury. They are obtained either from bone marrow, adipose (fatty) tissue or blood. They can also be taken from umbilical cord blood just after birth.

Scientists at Imperial College London rather take a conservative position, since although excellent progress has been made in solving basic problems, a significant amount of hard work and research remains to be done before these results are used in patients*. "The door is open to such treatments, and our studies are a step towards identifying the right cells to use", they say, “and haemophilia, the hereditary bleeding disorder which affected Queen Victoria’s family, might one day be treated by taking these cells from a patient and replacing the gene that causes the disease, then putting them back into the patient”** But they cannot say when.

Furthermore, even in scientific literature duplicate or overlapping reports may come to different conclusions when using different experimental designs (Francis et al. 2013). It is sometimes difficult to ascertain when research can be put in clinical practice until the differences have been resolved.

* Scientists overcome obstacles to stem cell heart repair, Group is working on harnessing stem cells to build patches for damaged hearts - Imperial College London News Release, 13 Dec 2007

** Stem cells enable personalised treatment for bleeding disorder, Imperial College London News Release, 5 April 2013

This is the true scientific position, and contrasts with some unscrupulous assertions.

Some commercial enterprises offer treatments guaranteeing maximising abilities of infants with Down syndrome, even mentioning “numerous Down syndrome children” in several countries with a “statistically satisfactory improvement” in many instances. However, we shoul be vey careful of such claims as no clarification is made in terms of the degree of confidence obtained in that improvement. A true scientific study makes an analysis of the degree of confidence of data and specifies clearly the size of the sample; there is always a distinct possibility of failure, particularly when dealing with such a complex system as a human being, so “statistically satisfactory” and “numerous” are meaningless in their assertions. Furthermore research designs are sometimes absent or unsatisfactory as not all relevant variables may be controlled.

They sometimes go as far as saying that in spite of textbooks stating that “genetic disorders” have no known treatment, with their methods children with Down syndrome have systematically improved on each occasion. Some “scientific reports” are quoted in their websites, but they were not submitted to an international respected peer review but belong to private and closed clinical trials with no scientific control methods, therefore, they lack validity.

For all the above, we advise parents and others to be cautious with such advertisements since they may signify a waste of money and worse lead to a frustration of parents and families for unfulfilled hopes.

It is wise, however, to be vigilant and keep abreast of developments and consult with appropriately qualified and recognised specialists.

8

PHYSICAL CHARACTERISTICS AND HEALTH ISSUES

Margaret Kyrkou and Manuel I Guerrero

Health and wellbeing are fundamental for the child's development

INTRODUCTION

Children with Down syndrome may need treatment during childhood, but then usually are healthy. In this chapter, we will describe conditions that are more frequently experienced by people with Down syndrome than by people in the general population. It is important to remember as you read that a person with Down syndrome will not experience all of these conditions. Also, most are treatable and so with good health care, people with Down syndrome can expect to lead healthy lives. We offer this chapter to assist carers to know what to look out for and to know what concerns to raise with health care professionals.

After serious surgery, doctors always give advice on the post-operational process, what to do and what to avoid in order for the person to enjoy improved quality of life. With a detached retina, doctors take good care to provide periodic check-ups. After surgical interventions professionals may provide advice including care and exercise, but in spite of that acquired disability a good life is still possible.

Down syndrome, due to its overabundant chemical signals resulting from an additional chromosome, requires that parents as well as health professionals watch out for changes in bodily functions. This information on health issues is provided not to supplant professional advice, but to make parents aware when to seek that advice.

In what follows, the most common health issues are mentioned so advice from the general practitioner should be sought if a parent is worried something may be wrong, then the GP may refer the child to a specialist. These are the most common health issues, but any child is very unlikely to have them all, on the contrary normally just a few of them are present and in a variable degree of severity, depending on the person. Some issues would

not be apparent at all but during the routine visits, a GP may recommend additional assessments.

Some physical characteristics

There are some physical characteristics associated with Down syndrome. Many of them have no impact on the health of the person, and usually just a few are present, never all. These characteristics arise from the extra chromosome material. When Dr Langdon Down identified the syndrome now bearing his name, he identified a dozen characteristics (Down, 1866), amongst them rounded cheeks and laterally extended, slanting eyes, large tongue and small nose, which in time became the archetype of a person with Ds. He also mentioned thick and indistinct speech, noting, however that much could be improved by "a well-directed scheme of tongue gymnastics". Body coordination was defective as well, but "considerable manipulative power may be obtained by systematic training". Poor blood circulation was noted, particularly in cold months, but he went as far as saying that "their mental and physical capabilities are, in fact, *directly [related] to* the temperature". This of course is debatable given present knowledge. We also now know that the tongue is not large, rather the mouth is small.

In any case, he commented that "The improvement which training effects in them is greatly in excess of what would be predicted if one did not know the characteristics of the type" and that is precisely the purpose of this section, to offer basic information on the main aspects that should be afforded special care in order to prevent health problems.

Before the wide spread knowledge of DNA techniques, diagnosis was based upon apparent signs. Not all are present in every person, since as with anyone, heredity and environment each play their part, however the chemical imbalances manifest on some of these signs.

Common physical traits include low muscular tone, small head with a flattened back, excessive skin at the nape of the neck, flat nasal bridge, epicanthal folds at the corners of the eyes, upward-slanting eyes, spots on the iris, small ears, single transverse crease across one or both palms, and a short fifth finger which is slightly bent. The neck is short, as are arms and legs

compared to the size of the torso. The feet are wide with short toes, and the separation between the big toe and the others is larger than usual. The navel may protrude as in an umbilical hernia but it retracts with time, with no long term consequences.

The mouth is often small and lips are thin, but the tongue although usually normal size, appears relatively large; this together with a pronounced palatal arch can contribute to difficulty with speech production and to the tendency of the tongue protruding. Low muscular tone of the jaw can lead to difficulties keeping the mouth closed. In turn, this can lead to the tongue drying out and enlarging. Breastfeeding has been shown to reduce these effects and these benefits remain even after weaning. Among many benefits for the growing child, breastfeeding develops the muscles of the jaw and face, and supports the development of speech (ABA, 2014).

All of these features can occur in the general population; it is only when many are present in the one person that Down syndrome is suspected. None of the above individually brings about major health consequences. But there are other aspects in which it is important to be very much aware and these will be raised in the next section.

The most common health issues

Although there is a considerable range of medical challenges, not all people with Ds experience them. Some are common and represent potential dangers if not given adequate attention. In the table below some of the most important of them are mentioned. More information may be found at the American Academy of Pediatrics (Bull, 2011).

The most common medical concerns in Down syndrome are

1. Hearing: ear, nose and throat
2. Sleep apnoea
3. Speech and language difficulties
4. Vision
5. Heart
6. Mouth and teeth
7. Glandular problems

8. Gastrointestinal tract occlusion
9. Blood issues
10. Skeleton and joints
11. Other issues

Naturally not all of the issues represent the same risk or affect the quality of life the same way, but that does not mean they could be ignored, so a general description follows. It is beyond the scope of this book to be comprehensive; our purpose is only to raise awareness on these important issues. An excellent discussion in detail is found in Cliff Cunningham's book (Cunningham, 2006), particularly Chapter 7, Physical Characteristics and Health, and part of Chapter 10, Intelligence, Development and Attainments. See also the website of the National Down Syndrome Society (2012) for a very detailed discussion on health issues and references therein. Another good reference is a publication (in Spanish) by the Spanish Federation on Down syndrome (*Federación Española de Síndrome de Down*) and authorised for its publication in Mexico through Down-Town Puebla, A.C. (Fundación Española de Síndrome de Down, no date)

About two-thirds of babies are born with low muscular tone, that is, they have a great flaccidity for some to the extent of being necessary in the early weeks to feed them by artificial means since they cannot suckle the mother's breast. With patience, time and support, the majority of babies with Down syndrome learn to breastfeed and this should be encouraged. Some have a very weak cry or no cry at all so it is important for the parents to learn to interpret their signs that usually would be expressed by crying, to avoid them suffering for conditions such as pain or hunger. Later on, muscular tone improves but a regular exercise programme is often necessary to help increase strength and to improve coordination and motor skills. It is interesting to note that people with Down syndrome often retain great flexibility.

In a not so distant past, some of the problems referred to here were sufficiently severe to cause premature death, generally in the early years of life. Nowadays, with the exception of some severe cases, most of the problems may be corrected in time to an acceptable degree by means of surgery, therapy or exercise. When possible, it is necessary for the child with Ds to have the suggested

correction in order to increase the likelihood of success, and to respect the person's dignity.

HEARING: EAR, NOSE, AND THROAT

Ear, nose, and throat problems are common in children with Down syndrome. It is important for parents and family to be aware and consult with physicians as soon as possible, since many of these problems are present throughout the life of an individual. The otolaryngologist plays an important role in the health of a child with Down syndrome, since those problems have repercussions for physical, emotional, and educational development. It is important to get the opinion of specialists expert in Down syndrome.

Almost all children have problems with speech which may be due to oral anatomy (e.g., relatively large tongue), muscle control as well as hearing difficulties. Another reason, besides the physical aspect is the lack of maturity of the appropriate brain zone where grammar is processed. Sometimes hearing difficulties go unnoticed. If facilities are available, babies with Ds should have a hearing assessment within the first 6 months of life to determine if inner ear hearing deficits are present. Subsequent hearing assessment every six months can detect middle ear conductive hearing loss which is very common in many children and particularly so for children with Down syndrome. When a child does not respond to language or sounds as expected, it is then wise to have hearing assessed, since opportune intervention often leads to improvements in speech and behaviour, whereas untreated can eventually lead to withdrawn or asocial behaviour.

Hearing loss can also affect general education, language, and emotional development. Even mild hearing loss can affect a child's articulation. Monitoring and treatment of the ears and ear diseases can lessen the incidence of hearing loss, but sometimes more complex remedies are recommended such as hearing aids or surgical intervention. Hearing aids should be considered even with mild hearing loss to prevent delays in educational, emotional and language development.

Narrow ear canals are common and make the diagnosis of middle ear conditions difficult. It is often necessary to have them cleaned by a specialist since careless cleansing may harm those delicate canals. They grow with age and may no longer be a

problem after three years of age but three-month checks are advisable to avoid undetected infections. An inflammation or infection of the middle ear may cause a glue-like fluid to build up behind the eardrum, in the normally air-filled middle-ear space. This is a common childhood infection sometimes requiring a surgical procedure, but due to the facial anatomy of people with Down syndrome it tends to last longer than in the general population; so the ears and potential infection should be monitored regularly. The use of grommets (small tubes inserted in the ear drum) has been found to be particularly effective and can minimise the effects of hearing loss. Within the ears there is a fluid; initially it is thin and watery but gradually it becomes like a thin jelly (or glue) and hearing is affected. This happens more frequently in children with Down's syndrome than in the general population.

Low muscle tone affects the opening and closing of the Eustachian tube from throat to middle ear, which can cause negative pressure to build up in the middle ear space, leading to more fluid retention and the possibility of infection. An excellent website for a detailed discussion that may be of help is http://www.dsmig.org.uk/library/articles/dsa-medical-series-4.pdf

Sleep Apnoea

Another problem related to the above is the airway obstruction which happens during sleep, known as sleep apnoea and meaning not breathing for short episodes during sleep. This can be caused by the small upper airway, or large adenoids and tonsils, as well as low tone of the muscles of the throat and a larger tongue falling back into the (small) airway during sleep. As the oxygen in the blood diminishes the child will awake, often with a start.

There are indications that somewhere around half (some studies say all children) with Down syndrome have obstructive sleep apnoea, and it seems that it increases as children grow older, particularly in obese individuals. Loss of sleep or poor quality sleep can result in sleepiness, disturbances in fine motor skills, and disturbances in behaviour and learning. Many with sleep disorders fall asleep with passive activities such as riding in the car or in a school bus. As long-term complications may be serious, it is important to undergo a sleep study if sleep apnoea is suspected, in order to obtain appropriate treatment.

Most children are predisposed to sleep apnoea due to the facial anatomy of Down syndrome, which together with allied problems with the developing immunological system, predisposes the child to chronic inflammation of the mucus and sinus membranes of the nose. Treatment includes the use of saline drops or spray to keep the smaller nasal passages clear as well as the use of antihistamine medications and steroid nasal sprays. These issues should improve with age and can usually be managed by the general practitioner, but in children whose problems fail to resolve with medical management, surgical removal of the adenoids may be necessary.

Sleep disturbances can be serious when they affect cognitive abilities, behaviour, or growth rate. When they give rise to high blood pressure in the arteries of the lungs or the heart, coupled with the congenital heart problems they may put the life of the child in jeopardy.

Parents are usually not aware of these risks, so it is highly recommended they learn about the symptoms and have the child examined when they occur. Symptoms that are suggestive of sleep abnormalities include mouth breathing while sleeping, restless sleep, snoring, heavy breathing, uncommon sleep positions, frequent waking up during the night, excessive daytime sleepiness, lack of energy, and behavioural problems associated with poor sleeping. Sleep positions such as sleeping sitting up, sleeping with the neck extended, or sleeping bent forward at the waist in a sitting position are all suggestive of a sleep disorder or obstructive sleep apnoea. In this case the general practitioner would generally refer the child to a specialist.

Speech and Language Difficulties

Anatomical aspects related to ear, nose, and throat pose difficulties for speech and language, a common problem. The assistance of a speech therapist will help most children with these problems. Others might have continuing difficulties in mastering language, particularly syntax and grammar, which requires development of parts of the brain which lag behind the child's general ability. This is a major challenge. It is common to see a 5 year old with unintelligible speech having other abilities quite well developed. Furthermore, their speech sounds like a language but is not intelligible or at best difficult to understand for strangers.

This frustrating situation can be compared with a typically developing person trying to communicate in a foreign language, with the inability to do so leading to social challenges. It is important to encourage expression by other means such as signing, until they develop the necessary communication skills, which may remain limited to varying degrees amongst individuals.

A way to reduce the difficulties is to encourage non-verbal ways of communication, which include facial expressions, body postures, and hand and eye movements. This can become tiring for all, so take turns with others present, and also try to clarify ideas by asking for repetition. Communicating is engaging in socialising, so the parents need to read the signs from the baby and try to decipher what he or she is communicating, as is done with any young baby still unable to speak: parents learn to distinguish between different ways of crying for example. As the baby grows older, needs increase, and more complex communication is required. Here sign language might be a useful tool. Studies indicate that sign language not only does not preclude spoken communication but rather encourages it by reducing the frustration to express themselves. Furthermore, there are indications that sign language can enlarge vocabulary. It is important to make the sign and pronounce simultaneously the word describing it.

Therapists can give advice on the kind of sign language and provide elementary courses for parents and family.

A few rules are useful:

a) Speak clearly and slowly: wherever possible point out what one is referring to.
b) Simplify the message; if necessary divide it into simpler parts.
c) Give the person more time to process the message
d) Do not press for an answer.

A good idea is to place signs in appropriate places: for example the kitchen, bathroom or any other appropriate places in the house. This facilitates the development of appropriate associations.

VISION

Down syndrome is more frequently associated with visual difficulties. Approximately half of babies present some kind of

problems ranging from slight to severe, so immediate action must be taken to prevent diminished vision, which would be a serious barrier for development in other areas, since the information they would receive would be diminished. A major problem is cataracts which consist of opacity on the crystalline lens which the eye uses to focus – cataracts are common in persons of advanced age, but in babies with Ds they may be present at birth. Whilst an adult may safely postpone surgery, significant cataracts presenting early in a child's life and not removed in time can result in lifelong poor vision. This lack of clear images may mean the brain does not receive the information correctly and the area related to vision develops poorly. In such situations the cataract should be removed promptly in order to avoid permanent damage, which is why early detection of cataracts in infants and children is so important.

A consequence of the low muscular tone in vision brings a tendency to squint or strabismus in which the two eyes are not able to focus on the same point, which adds to problems with general appearance. The infant can be helped to correct this defect by focusing sight at a given point. If the problem persists beyond a year of age it is important to seek the advice of an optometrist or eye specialist, since glasses alone may simply not be enough to straighten the eyes. If the eyes continue to show a squint despite corrective eyeglasses, eye muscle surgery may be advisable, a simple procedure lasting a couple of hours as an outpatient. Squint needs to be treated before the age of 7 years, as after that the brain can permanently suppress the vision in one eye to avoid the difficulties associated with double vision. Loss of vision in one eye results in difficulties with eye hand co-ordination, and impairs depth perception.

A simple test to detect some of those problems is the "red eye test", the effect obtained when photographing a subject and the flash light bounces back on the retina giving that peculiar appearance of the eyes. The same principle is used to diagnose easily some problems in children with Ds: if the back of the eyes do not look red – as is normal – the child should visit a paediatric ophthalmologist (see for example O'Dowd , 2013 and Nye, 2014).

The shape of the eyes and spots, which can be seen in people without Down syndrome as well, do not affect vision. The channel draining tears towards the back of the nose may well be

blocked and result in watery eyes when not draining properly and thus retaining dirt. These in turn promotes infection, since the body is a system, and if something goes wrong with one part further complications are to be expected. It is thus necessary to clean the eyes frequently after consulting with a specialist who can recommend the best ways, because not every method of cleaning is appropriate. In the eyelids there are some ducts carrying tears to lubricate the eye which frequently get blocked (not only in Ds persons) leading to dryness in the eyes in a condition known as blepharitis. Applying eye drops is not a remedy and may worsen the condition; a gentle massage on the eyelids followed by cleansing with purified water with a bit of salt or baby shampoo in the inner side of the eyelids unblocks the ducts by dissolving the secretions.

The need for glasses is more common in children with Down syndrome than in the general population due to optical or refractive errors resulting in focusing light not on the retina but in front or behind. These errors result in blurry vision, two most common of which are nearsightedness and farsightedness**.** Nearsightedness is easily corrected with a concave lens whereas farsightedness is also easily corrected with convex lenses which cause light rays to converge prior to hitting the retina.

Less common optical errors occur when the optical power of the eye is too strong or too weak across one axis. The most common errors of this type are astigmatism and presbyopia. People with astigmatism see contours of a particular orientation as blurred, but see contours with orientations at right angles as clear. Presbyopia happens when the flexibility of the lens declines typically due to age. Individuals experience difficulty in reading causing eyestrain. This causes the individual to need visual assistance such as bifocal lenses.

HEART

Heart problems are common: between 30 and a 60% of babies suffer some kind of heart problem and about 15% have severe problems and because of the risks they must be dealt with promptly (Cunningham 2006). Whereas some babies would not survive without opportune surgery, others will not require treatment beyond careful checkups.

There are four common defects, two within the heart, one channel between the pulmonary artery and the aorta, and one involving oxygenated with deoxygenated blood resulting in low blood oxygen.

Defects within the heart result in a murmur, normally detected in early infancy. Sometimes these defects correct themselves with time, others require surgery.

The channel between the pulmonary artery and the aorta exists during foetal life; it diverts blood away from the lungs because prenatal blood is already oxygenated from the mother. After birth this channel usually closes on the first day of life. If it does not close, it is termed "persistent" and results in an increased flow of blood into the lungs. Again microsurgery is performed with a high degree of success.

Children with heart defects have difficulty breathing and a general lack of energy, possibly not so much when they are very young, but it becomes more and more apparent with time, thus it is important that all children born with Down syndrome, even those who have no symptoms of heart disease, should have an echocardiogram in the first two or three months of life. Some heart conditions are also identified during prenatal ultrasounds.

Heart surgery to correct the defects is recommended and it must be done before the age of five or six months in order to prevent lung damage. Although the complexity of the defects raises the risk of surgery slightly above that of surgery on children without Down syndrome, successful surgery will allow many children with heart conditions to thrive as well as any child with Down syndrome who is born with a normal heart.

However heart problems do not preclude children from participating in physical activities, with of course previous consultation with the doctor and parental supervision, as in any other major health problem.

MOUTH AND TEETH

Dental care is important for everybody, but particularly for people with Down syndrome since their teeth – both baby and permanent – are frequently cut later than other children, and sometimes in a different order. Teeth are frequently smaller than average and some are missing, and it is also common to have shorter roots.

Their shape may be irregular, sometimes pointed, and in unusual positions.

Small teeth, unevenly spaced and a small upper jaw frequently cause problems with bite. Braces, or orthodontics, may be able to improve some of these issues but it requires a lot of cooperation from the patient and causes an additional difficulty in maintaining proper dental care. It also may cause speech difficulties which may be already an issue for other reasons. It may be advisable to delay this treatment if the problems with bite are not major. Of course, young people with Down syndrome are conscious of their looks and if they are concerned about the appearance of their smile, they may be motivated to undergo the challenges of braces.

People with Down syndrome are prone to gingivitis (gum disease) at higher levels than others in the population. This appears to be due to different types of bacteria present in the mouth but the reasons for this difference are not clearly understood (Khocht et al, 2012). To prevent or treat gingivitis, it is wise to brush more frequently and focus the bristles along the gum line, floss daily and visit the dentist regularly. If available, electric toothbrushes are found to be more effective than manual brushes, and have the added bonus of allowing the person to become accustomed to vibrations in the mouth. This is helpful should dental work be required.

Cavities or dental caries are rare in people with Down syndrome (Davidovich et al, 2010), but they can occur, so regular check-ups at the dentist are recommended. Prevention is simple: brushing with fluoride toothpaste, flossing between any teeth that touch, and limiting the amount and frequency of sugar and refined carbohydrates eaten. Sugary carbonated drinks should also be avoided.

Having noted these points it is also important to select a dentist with care; someone who understands the particular dental problems of a person with Down syndrome and a dentist who is good and at ease with children, which might prove to be difficult in some countries. Some Down syndrome associations have made a list of dentists who are familiar with and happy to work with children with Down syndrome.

Individuals with Down syndrome have a higher incidence of glandular problems than the general population, particularly the thyroid, adrenal and pituitary glands. A malfunctioning thyroid gland decreases the synthesis of a hormone which promotes growth of the brain and other body tissue, hence the importance of timely diagnosis.

Thyroid disease is the most common glandular problem in children with Down syndrome; approximately 10% of children may have congenital or acquired disease. In adults the incidence may be as high as 50%, and it can occur at any time from infancy through to adulthood (National Down Syndrome Society 2012). A thyroid function blood test should be performed at birth and at periodic intervals (at least every two years) thereafter, since the indicators of low performance of this gland: sparse hair on the head, enlarged tongue, constipation, poor circulation and low motivation are also found in individuals who do not have it. The fact that this is still overlooked in people with Down syndrome is of concern, since once detected it can be readily corrected by replacing the insufficient amount of hormone through medication.

The opposite problem, when the gland is overactive, may also be treated by medication, but this problem is no more common in people with Ds than in the rest of the population and in some cases a surgical removal of part of the thyroid gland may be advisable.

Other glandular problems include diabetes, which is seven times more common in children with Ds supposedly due to an enzyme produced by genes on chromosome 21 that is involved in the production of glucose and correct metabolism, so it is important to note whether the common symptoms of frequent urination, tiredness and excessive liquid and food consumption are present. There are two types. Type 1 develops in childhood and requires insulin to control it whereas type 2 appears later in life, and is associated with obesity, sedentary lifestyle, lack of physical activity and an imbalanced diet. Type 2 has increased markedly over the last 50 years in the general population because these three factors are becoming all too common in modern life.

GASTROINTESTINAL TRACT OCCLUSION

The gastrointestinal system includes all the parts of the body involved in the processing of food. Most individuals with Down syndrome have a normal gut, but from 2 to 8% have an increased likelihood of developing medical conditions that interfere with digestion. Most may be treated by the general practitioner; others might require the added recommendations of a specialist. A few infants are born with no open anus from which the stool can be passed. This is easily identified when a baby is examined for the first time and is corrected with surgery. Between 2 and 15% of infants are born with a condition called Hirschsprungs, resulting in their large intestine not functioning properly due to a lack of certain nerve cells, and as a result, children cannot properly expel stools. Symptoms in early infancy include a swollen abdomen, vomiting, and an inability to expel stools. This may also present later in life with severe constipation, in which case advice should be sought promptly.

Up to 16% of persons with Ds may have a condition called celiac disease (which some without Ds have as well) and means they are intolerant to a protein (gluten) found in barley, oats, rye and wheat. A blood test may confirm if this condition is present or not. If it does, a gluten-free diet for life is necessary.

Some babies with Down syndrome breastfeed with no difficulty but for some babies with very low muscular tone, breastfeeding may take time to establish since it represents strenuous effort. This may be overcome with advice from lactation specialists. Breastfeeding and breast milk have important benefits for all babies and especially so for babies with Down syndrome. The properties of breast milk that boost immunity and maintain healthy gut flora cannot be matched by other milks and the benefits last long after weaning. In the weeks and months while breastfeeding is being established, expression of breast milk is encouraged. This helps the milk supply to be established and the baby to receive the optimal nutrition.

A trait usually observed is a tendency to be obese, and apparently weight problems are common sometimes due to hypothyroidism or a lower rate of metabolism and because of a high consumption of calories coupled with little or no exercise. However this last reason is not limited to persons having Down

syndrome, but it is becoming a serious public health problem. Thus it is important to develop a healthy diet and exercise habits to prevent obesity, which in turn may lead to other health complications such as high blood pressure and diabetes.

BLOOD ISSUES

Some studies suggest that people with Down syndrome tend to have poor blood circulation, maybe because of their thin arteries, though most children do not have this problem. However poor circulation could mean less oxygen being transported due to heart problems. Caressing babies has the effect of stimulating circulation and at the same time makes them feel loved, but it has to be done gently, particularly rubbing the extremities.

It has been suggested that there are deficiencies in the red blood cells responsible for carrying oxygen, in the white blood cells responsible for controlling infections and in platelets (responsible for stopping bleeding) that resolve spontaneously with time. In some cases an evaluation by a specialist might be necessary.

The most common problems that warrant consultation with the specialist are enlargement of red cells, which persists throughout life in about a third of persons, and can be related to hypothyroidism, a low number of white cells that may increase the risk of infections although it has not been proved beyond doubt, and a reduced number of platelets which may predispose to bleeding.

There is an increased risk of developing cancerous conditions like leukaemia (a cancer of the blood cells) which spreads to other parts of the body. While the risk of contracting leukaemia is higher for children with Down syndrome, their rate of recovery is much higher than for other children. The cause if this is the subject of current research in the hope of improving the survival rates of all children.

Other problems but with less significance for health and welfare are an elevated number of red cells which may be associated with some heart problems, but mostly will not cause significant problems. Some individuals may need to be treated if the number of red cells is extremely elevated and the blood gets too thick. Elevated number of platelets or white cells usually resolves spontaneously unless there is an additional problem.

SKELETON AND JOINTS

Bones, muscles and joints

The main problems with this system arise from the low muscle tone mentioned above. Muscle tone is the passive and continuous contraction of muscles that make them resistant to stretching and thus maintaining body position, so if tone is low, muscle response is impaired. In addition, ligaments tend to be lax and easily stretched.

Consequences are multiple: when the condition is severe feeding a baby may prove to be difficult; with sitting up and walking delayed. Eye control can also be difficult, though usually these problems are corrected with age and exercise recommended not only to strengthen the body but to contribute to socialising and strengthening the sense of belonging to a team. Swimming, climbing, gymnastics, horse riding are good practices.

When travelling by car particular care should be taken to ensure the head has adequate support with the seat belt always fastened. It is always good practice for all children, but having poor muscle tone makes it even more important in the eventuality of sudden braking.

Many of the bone manifestations originate from malformations of the skeleton due to the extra genetic material. Eye orbits have an oval shape giving rise to skewed eyes; the nose bone does not develop completely giving the appearance of the face flat; jaws are small resulting in a small mouth and occasionally the lower jaw is larger than the upper causing an uneven bite, so the mouth then tends to be kept open. Inner channels in eyes, nose and mouth are small so they are easily blocked and may cause problems with vision, hearing and breathing. It is wise to visit a professional regularly to avoid damage and infections, some of the common problems associated with people with Down syndrome.

However it is necessary to be on the lookout for potential dangers, particularly with the neck which may be not well supported due to muscle weakness.

Atlantoaxial instability

The head is attached to the spinal column by a column of small bones piled one on top of the other forming the neck. Through it all nerves pass, communicating signals to and from the brain. The spine needs flexibility as well as strength, accomplished by a series of complicated joints, the main one of which is the atlantoaxial at the upper part of the neck between the first and second cervical vertebrae. It is of a complicated nature since it consists of more than four distinct joints. In individuals with Down syndrome, the laxity of the transverse ligament may cause problems, including clumsiness, lack of coordination, abnormal gait, difficulty walking, easy fatigability and neck pain among others. This is known as atlantoaxial instability and as in many other manifestations of Ds there is no apparent racial nor sex predilection.

Because of the potential serious damage, much attention has been given to atlantoaxial instability, particularly when the individual wishes to be engaged in sports activities. Apparently the risk has been overestimated as well as the traditional diagnosis with neck X-rays; if this instability is suspected magnetic resonance imaging is a better tool. According to Cunningham some leisure activities of children have been restricted unnecessarily, but it is however, wise to check this out medically, even though it is frequently not a problem.

OTHER ISSUES

Skin

Poor blood circulation may lead to impaired body temperature control: persons with Ds cool down more quickly and respond less to heat. It has to be taken into account for example when swimming, but apart from this there is nothing good clothing cannot correct. However, children must feel free to play, and cumbersome clothing may prevent good quality play, but after exercise they should be protected against sudden cooling.

Skin tends to be less elastic, and suffer from dryness causing roughness, particularly on lips, cheeks, hands and feet, and causing discomfort. Frequent washing with neutral soap and the

use of dermatological creams provides good care. Adolescents experience fewer skin problems, such as acne, than their peers.

Hair may be thin and sparse and due to dryness on the scalp it may be further shed. It is advisable to seek advice from a hair dresser for appropriate shampoos and hair treatments, since appearance is as important in people with Ds as for anyone.

Mental health, behaviour, anxiety

For many years mental health problems of people with Down syndrome were ignored since they were considered as part of the syndrome. It is now recognised that psychological disorders are found less, however it is estimated that between 8 to 15% of children and 22 to 29% of adults have signs of mental health problems, some severe enough to be of concern (Cunningham 2006, p.299). The most common include general anxiety, repetitive and obsessive-compulsive behaviours; oppositional, impulsive, and inattentive behaviours; sleep related difficulties; depression; autism spectrum disorder; and neuropsychological problems characterized by progressive loss of cognitive skills.

The pattern varies depending on the developmental characteristics, so for example children with limitations in language and communication skills, cognition, and non-verbal problem-solving abilities present with increased vulnerabilities in terms of disruptive and oppositional, or anxious, inflexible and repetitive behaviours. Later in their life they may be depressed and socially withdrawn, and as adults may be generally anxious. Much of this may be due to social isolation and lack of inclusive life styles as adults, or at least it can be a contributing factor.

Such behaviours may be triggered by an environmental stressor, such as illness, separation from or loss of a key attachment figure. Children and adults with Down syndrome are often exquisitely sensitive to psychosocial and environmental stressors, and consequently such factors are particularly devastating. Appropriate counselling and appropriate medication can often help, unless the problem is more severe in which case a psychosocial and cognitive functioning decline may be suspected. If that is the case there is still a wide range of available screening and diagnostic tools for assessment of mental conditions to find an appropriate intervention which may include behavioural

modification, pharmacological intervention, recognition and management of delayed emotional development, and social skills training.

Ageing and Alzheimer's disease[*]

Regarding ageing and Alzheimer's disease, it has been found that several genes on chromosome 21 are involved in the aging process, accelerating ageing in persons with Ds, and also contributing to the progressive impairment of memory functions known commonly as Alzheimer's disease. This property of chromosome 21 poses a higher risk for people with Down syndrome since they have a triplicate copy of this chromosome, yet it is not manifested in all persons with Ds. Since it is characterised by a series of changes in the level of functioning, if some worrisome observations such as sensory losses, hypothyroidism, obstructive sleep apnoea, osteoarthritis, atlantoaxial instability, osteoporosis or celiac disease are observed a medical assessment should be sought since Alzheimer's disease is a clinical diagnosis. Unfortunately depression is sometimes confused with Alzheimer's and medical conditions so psychological assessment is important to make the correct diagnosis (National Task Group on Intellectual Disabilities and Dementia Practice, 2012).

Puberty and menstruation in females with Down syndrome

Parents of females with Down syndrome often report both physical and behavioural differences compared with their non-disabled siblings, and compared with reports on females in the general population, differences not reported in the literature. A Doctoral Study (Kyrkou, 2009). found retrospectively 48% of 28 females with Ds had breast development as one of the first signs of puberty at a mean age of 8.7 years. A further 44% had pubic or axilliary hair as the first sign of puberty at a mean age of 9.7 years. The most surprising finding was that 7.4% of the females with Ds had no signs of puberty until their first period, at which time other signs of puberty became obvious. The literature for females in the general population advised that the first period (menarche) occurs

* See chapter 6 Getting older and enjoying later life

two years after the first sign of puberty, but 16% of the females with Ds had less than a one month time span from the first sign of puberty to menarche, 52% reached menarche in less than 12 months from the first sign of puberty, and the remainder in less than 24 months. Cyclical symptoms occurred preceding menarche in 43% of the females with Ds, commonly for about 12 months, but in some females up to 30 months. Parents reported mood swings, irritability, being uncooperative, with lower abdominal pain, back pain, vomiting, bladder accidents and diarrhoea. These symptoms reduced as menarche approached, then ceased with menarche. A few of the females had similar symptoms preceding each period.

Mean age of menarche was 12.1 years. 75% of the females with Ds had regular menstrual cycles, and many were able to independently manage menstruation. It is important for professionals to alert parents to the shorter time frame from puberty to menarche, to allow adequate time to train the female in all aspects of managing her period including disposal of soiled pads. This lament from the mother of a female with Ds illustrates the distress caused when she was told menstruation was a long way off: '*At ten years we were informed by the endocrinologist that she wasn't reaching puberty. Three months later she got her first period, so it was a real shock. I explained it to her then'.*

Pain in women with Down syndrome

Whilst 78.6% of the females with Ds were able to state they had pain when they were hurt or unwell, surprisingly only 28% of those were also able to state they had pain in relation to menstruation. Parents reported recognising the presence of pain with non-verbal indicators. In decreasing order of occurrence, they were not moving, less active, quiet, seeking comfort or physical closeness, loud crying, soft moaning, whining or whimpering, eating less or not interested in food, increased sleeping, withdrawn or less interaction with others, or being non-cooperative, cranky, irritable or unhappy. Some parents also reported facial pallor. Although the presence of pain should be independent of communication ability, twice as many females with good communication were given pain relief compared with those who had poor communication ability. This suggests the presence of pain

may have been overlooked if the female was not able to say she had pain, and non-verbal indicators of pain were not recognised. It is also important to be aware that even articulate people with Down syndrome, and particularly children, may not be able to interpret and report pain signals. If a cause is obvious, such as an injury, a good rule of thumb is to medicate to the extent you would for a person without Down syndrome. Do not just rely on the patient's reported experience of pain.

Risk Evolution Assessment and the Use of Information

A particular individual may have some but not all of the health issues described above and with varying degree of severity. Further-more some issues, although initially severe, such as a congenital heart defect, may cease to be risk factors when dealt with on time, a surgical intervention in this case.

Some health issues have implications for other parts of the body and it is important to understand that and how they may affect the child so that appropriate medical intervention may be designed. A malfunctioning thyroid gland decreases the synthesis of a hormone which promotes growth of the brain and other body tissue. A lack of this hormone might result in reduced intellectual capacity and inactivity which could have been avoided. This should always be checked as this condition tends to be quite common in Down syndrome.

So it is useful to record the main issues parents want to tell doctors in their periodical evaluation and to note whether the conditions persist, increase or decrease. This is easily done with a simple log which we will call a "risk evolution assessment" (REA). We see this can be a useful technique to serve as a log or report for parents to inform doctors about health matters to support a more precise diagnosis and take preventive actions in time.

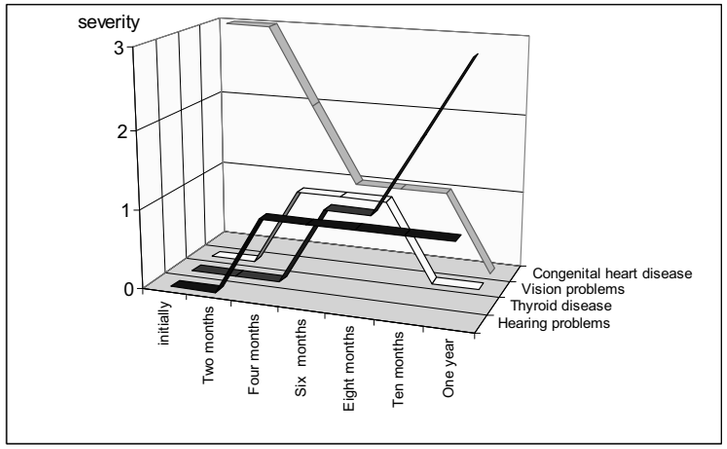
It consists of a table where all detected conditions are written in the rows of a first column and the following columns contain numbers assigned to the severity of each one, as time goes by. To make it simple we assign 0 to non existent, 1 to mild and 3 to severe; parents may not know how serious a condition is so they are labelled DK (Don't Know) and set aside until a diagnosis is given.

	At birth	Two months	Four months	Six months	Eight months	Ten months	One year
Hearing problems	0	0	1	1	1	1	1
Thyroid disease	0	0	0	1	1	2	3
Vision problems	0	0	1	1	1	0	0
Congenital heart disease	3	3	2	1	1	1	0
Teeth and dental care	DK	These columns are meaningless until information is available					
Speech and language	DK						

Table Risk Evolution Assessment

So, in our example the leading condition at birth is congenital heart disease which doctors treat mostly surgically and by the fourth month it is corrected, so from there on the severity of symptoms decreases until having little impact by the end of the year. Hearing problems begin to become obvious by the fourth month but remain stable; thyroid disease however becomes the leading condition for severity towards the end of the year. Vision problems are revealed but corrected with glasses.

For those computer-oriented it may be useful to represent the table in a graph which makes it easier to see at a glance. Something like this can be done with any spreadsheet. Simple or more complex recorded information can benefit everyone - child, parents and professionals. If you find the setting up a challenge, ask someone at your nearest Down syndrome association.



END NOTES

The attention to health issues is an important factor in the quality of life of a person with Down syndrome. As we noted at the beginning, most people with Down syndrome who have access to medical care are very healthy. The above is a brief listing of some common problems to assist carers to be prepared and informed.

People with Down syndrome have some conditions that have to be monitored appropriately by professionals, but having said that the parental and family love, care and monitoring as given to any child should be sufficient to have them kept in good health. Regular visits to appropriate health care professionals should be made, and for specific information consulting the links provided at the end of this book may be of help.

Part three

SUPPORT POLICIES

Disability is part of the human condition and may happen at any time along life span: almost all people will suffer some type of disability-transient or permanent-at some point in their lives. More than one billion people around the world live with some degree of severity and among them almost 200 million with considerable difficulties in functioning (World Health Organization, 2011).

Despite this harsh reality, society prefers to turn its head to the other side and forget people with disabilities. For all these reasons, values must be anchored in policies that promote the well-being of those most vulnerable members of society. So that the policies do not remain as good intentions, it is necessary to suggest the path by which they can become practices. The concepts of quality of life, presented in chapters 2 and 3, and the Convention on the Rights of Persons with Disabilities establish useful guidelines for this purpose. In the next chapter, the authors analyse the development of policies and their application in a changing environment, taking into account these elements.

This third part closes with a very personal exposition of the author who participated in the working groups that made the Convention a document that the countries recognised and adopted as their own, and bind them to ensuring that people with disabilities are treated as anyone else. Unjust laws will be changed and everyone ought to be included in their policies. In 2016, on the tenth anniversary of its adoption, 160 countries had signed it and 92 had adopted the optional protocol, which recognises the competence of the Committee on the Rights of Persons with Disabilities to receive and consider complaints about any violation by governments.

9

POLICY DEVELOPMENT AND ITS APPLICATION IN A CHANGING ENVIRONMENT

Robert L. Schalock and Miguel A. Verdugo

INTRODUCTION AND OVERVIEW

Policies drive practices, and practices influence people's lives. Currently, the time is right for jurisdictions throughout low and middle income countries (LAMIC) in Latin America to critically analyze policies toward people with disabilities, and align current and future policies with not only the UN Convention Articles concerning the rights of people with disabilities, but also the principles underlying the QOL concept—principles that embrace inclusion, equity, self-determination, and empowerment. How this might be done is the focus of this chapter, which discusses a framework for policy development and its application. The chapter is geared towards two audiences: those who live and work in low and middle income countries in Latin America, and parents and front line personnel who are major support providers to a family member with a disability.

Our goal and challenge in writing the chapter is to provide an overview of how policy can be developed to enhance the lives of individuals with various kinds of disabilities (e.g. Down Syndrome, Intellectual Disability, Autism Spectrum Disorder), and then describe specific strategies that policy makers, professionals, support providers, consumers and researchers can employ to enhance the personal well-being of individuals with a disability. We also suggest strongly that meaningful change will not come about without a partnership among these key stakeholders.

We begin the chapter with a discussion of an outcomes approach to policy development. In this section of the chapter, we summarize current thinking regarding outcomes-driven policy and contextual analysis, and explain how these two concepts can be used to develop public policies that are culturally sensitive and outcome oriented. In the next section, we discuss policy application that is maximized through a partnership among policy makers, professionals, support providers, consumers, and

researchers. We conclude the chapter by discussing the conceptual and values-based foundation of the proposed approach to policy development and its application, and suggest five steps for developing and applying disability policy in a changing environment.

An Outcomes Approach to Policy Development

We propose that policy development should be based on right to left thinking, which involves beginning with the end (i.e. desired outcomes) in mind. Such an outcomes approach requires an understanding of outcomes-driven policy development and contextual analysis.

Outcomes-Driven Policy Development

Policy development based on right-to-left thinking is at the heart of what has come to be described as outcomes-driven policy (Shogren et al., 2015; Turnbull & Stowe, 2014). As these authors discuss, most public policies related to people with disabilities have historically been based on humane societal concepts and values, and how best to implement these value-based policies through resources, statutory changes, service delivery framework, and managerial strategies (Schalock & Verdugo, 2012 a). To date, however, there has been more emphasis on process-driven policy formation than on outcomes-driven policy formation. Shifting to outcomes-driven policy development would maintain the current policy development practices such as basing policy on societal values and an implementation framework, but would add two critical components: a listing of desired personal, family, and/or societal outcomes; and a stipulation of best practices for implementing the policy.

Four current trends support the movement towards outcomes-driven policy. These four are an emphasis on human rights, the emergence of interdependency, the social construction of disability, and an emerging consensus on desired policy outcomes.

An emphasis on human rights

In a recent article entitled "The UN Convention on the Rights of Persons with Disabilities: Implementing a Paradigm Shift" Mittler (2015, p. 79) suggests that the UNCRPD, along with the new UN commitment to ensure the inclusion of people with disabilities in the post-2015 Sustainable Development Goals, provides an important catalyst for a radical reappraisal of policies and practices among governments, advocacy groups, organizations and services providing services and supports to persons with a disability, professional organizations, and researchers. Mittler proposes further that such a reappraisal, with accompanying actions, is an overarching priority for organizations and individuals committed to improving the quality of life of people with disabilities.

The UNCRPD (United Nations, 2006) is based on a number of principles that provide a framework for focusing global opportunities and thereby enhancing peoples' personal well-being. These principles include respect for inherent dignity and individual autonomy, equality and nondiscrimination, full and active participation and inclusion in society, accessibility, and respect for the evolving capacities of children with disabilities and the right to preserve their identities

UNCRPD-related global opportunities are further enhanced through a number of UN-related actions associated with implementation of the Convention. Chief among these are: (a) reporting progressive realization of a National Plan for action over a given period of time to the UN Office of the High Commission for Human Rights; (b) establishing guidelines to ensure that people with a disability are explicitly included in the whole range of UN-sponsored aid and development programs; and (c) including in the Sustainable Development Goals the assurance that the needs and benefits of all persons with disabilities will be taken into account in considering poverty eradication, social inclusion, full and productive employment and decent work, and basic social services (Mittler, 2015, pp. 80-82).

Emergence of interdependency

The world is becoming more interdependent. As Friedman (2015) noted, an interdependent world comes down to behaviors guided

by sustainable values such as humility, integrity, and respect that build healthy interdependencies. As an enhancement catalyst regarding outcomes-driven policy development, interdependency also
underlies our concern for the health, welfare, and safety of those around us; involves the reality that "what is good for all is also good for me;" and results in a vested interest in the lives of our fellow human beings.

Interdependency occurs at many levels. For example, a beginning has been made showing the relation between the Articles promulgated in the UNCRPD and both the core QOL domains and systems-level outcome indicators (Bradley et al., 2016; Claes et al., 2016). Other interdependencies occur when one partners with self-advocates and self-advocacy groups, involves people in decisions that affect their lives and actions, and places persons with a disability at the fulcrum of QOL enhancement activities. One also sees interdependency in the person-centered changes occurring in organizations, systems, and professional education and support provider training. Furthermore, interdependency is fostered when research includes consumers and emphasizes the evaluation of quality enhancement strategies and the determination of personal outcome predictors (Schalock & Verdugo, 2013).

Interdependency is at the heart of the relational world view that encompasses the belief that one "is" because others "are," and that a satisfying life is one in which one is a means of life satisfaction of others (Mpofu, 2016). Accordingly, personal well-being is explained and realized with and for the well-being of self and others, and when relational supports are interlinked to the mutual advantage of self and others. This perspective provides the rationale and basis for community-based rehabilitation (CBR) that is widely used in low- and middle- income countries. CBR strategies focus on community development, poverty reduction, equalization of opportunities, rehabilitation, promoting and protecting human rights, and the social inclusion of people with disabilities (Mpofu, 2016).

Social construction of disability

The social construction of disability is premised on the belief that disability is what a culture says it is (Rapley, 2004). This

conception of disability is changing to encompass the social-ecological model of disability, human capacities and their enhancement, the human rights of persons with disabilities, and the need for cultural competence in dealing with people with a disability. These changes also reflect the influence of international covenants on human rights, positive psychology, the effectiveness of self-advocacy, the supports paradigm, and the QOL movement (Mittler, 2015; Wehmeyer, 2013).

Table 1
Personal, Family, and Societal Outcomes

Focus	***Exemplary Outcome Domains***
Personal	-Rights -Participation -Self-determination -Physical well-being -Material well-being -Societal inclusion -Emotional well-being -Personal development
Family	-Family interaction -Parenting -Emotional well-being -Personal development -Physical well-being -Financial well-being -Community involvement -Disability-related supports
Societal	-Socioeconomic position (e.g. education, occupation, income) -Health (e.g. longevity, wellness, access to health care) -Subjective well-being (e.g. life satisfaction, positive affect (happiness, contentment), absence of negative affect (sadness/worry, helpless)

The social construction of disability has the advantage of offering a more optimistic future in which people with ID can have a better life. A social-ecological model recognizes that problems do not lie exclusively within the individual; rather, the individual may be disabled or disadvantaged through interactions with the

environment. Thus, outcomes-driven policy development requires a sensitivity to context (i.e. to the local culture) and to working within that cultural context. This emphasis on context is operationalized in contextual analysis which is described in reference to Table 2.

Emerging consensus on desired policy outcomes.

Disability-related policy makers, professionals, and support/service providers throughout the world are increasingly focusing on personal, family, and/or societal outcomes such as those listed in Table 1.

There are at least three reasons to focus on desired outcomes such as those listed in Table 1. First, these outcomes provide a conceptual and empirical link among disability principles, legislative initiatives, and legal trends occurring throughout much of the world. Second, they underscore why the clinical functions of diagnosis and classification are not ends in themselves; rather, as these two clinical functions are integrated into supports provision the anticipated outcome is the enhancement of human functioning and personal well-being. Third, relevant and valued outcomes form the ideology that motivates policy makers, funders, and other key stakeholders, and provide a framework for conceptualizing and assessing disability-related policy outcomes.

Contextual Analysis

A contextual analysis identifies the contextual factors that impact policy development and its application. A contextual analysis involves: (a) identifying the contextual factors that hinder change, (b) conducting a discrepancy analysis that identifies the discrepancies between where one is and where one wants to be, (c) identifying the forces for change that will increase momentum and receptivity, (d) identifying ways to promote policy application, and (e) identifying ways to increase stakeholder participation.

A contextual analysis is completed by knowledgeable respondents including the person with a disability, and is coordinated by an individual with knowledge and experience in service/support planning and delivery. This collaborative approach is consistent with assessment approaches such as participatory

evaluation, utilization-focused evaluation, and empowerment evaluation. The advantages of a collaborative approach to contextual analysis is that it not only provides an understanding of contextual factors that either facilitate or hinder change, but also fosters learning among participants and increases the likelihood that information obtained from the analysis will be incorporated into outcomes-driven policy and its application (Schalock & Verdugo, 2012 a; Shogren et al., 2015).

Table 2 presents an example of a contextual analysis *conducted within a QOL policy outcomes framework.* The first column lists the contextual factors that impact policy development and its application. The next three columns denote the three systems that affect human functioning and personal outcomes: the microsystem (i.e. the individual and their family), the mesosystem (i.e. education and service/support providers), and the macrosystem (i.e. the larger society). The material included in the respective cells of Table 2 is based on published literature (e.g. Manchester et al., 2014; Schalock & Verdugo, 2012 a, b; Schippers et al., 2015; Shogren et al., 2015) and the second author's extensive experience working throughout Latin America with consumers, families, service providers, professionals, and policy maker.

Results from a contextual analysis provide important information for policy development and its application. Those developing policies, for example, will be most interested in addressing the factors that hinder change, the differences between what is desired and what is seen, and the powerful mechanisms available for creating change. Those focusing on policy application will find useful information related to the analysis of the powerful forces facilitating application, the specific strategies/mechanisms that promote application, and the major stakeholders and how they can be involved in policy application.

In summary, this section of the chapter emphasized outcomes-driven policy that begins by identifying specific outcomes desired from disability public policy. Table 1 lists exemplary desired outcomes from the perspective of the individual, family, and/or society. We have also discussed the importance of conducting a contextual analysis that identifies the contextual

Table 2a
A Contextual Analysis Conducted within a QOL Policy Outcomes Framework

Analytic Component	*Microsystem*	*Mesosystem*	*Macrosystem*
Contextual factors that hinder change (What are the factors that hinder change?)	-:Low sociocultural level of families Reliance on "clinical approaches" instead of support approaches Lack of awareness of personal and family rights according to the UNCRPD Lack of a systems approach to analyzing problems and difficulties	Lack of organizations and representative networks that can influence public policy The inclusion paradigm in schools, employment, and society is currently mainly theoretical	Lack of implementation of the UNCRPD Public policies understood only from theoretical perspective Excessive presence of political corruption
Discrepancy analysis (What is the difference between what is desired and what is seen?)	Analysis of UNCRPD and support strategies available to the person and families at different ages Examine perceptions of parents and persons with disabilities and compare with reality	Analysis of inclusive situation (percentage through the years…) in education, employment, and social organizations Examine current knowledge, values, attitudes and motivation of staff Functioning of existing organizations/networks	Comparison based on UNCRPD laws and norms of the country and social reality (e.g. inclusion, equality, non-discrimination) Existence of public policies to secure rights; it is not just an individual matter based on personal finances

Table 2b
A Contextual Analysis Conducted within a QOL Policy Outcomes Framework

Analytic Component	*Microsystem*	*Mesosystem*	*Macrosystem*
Driving forces for change (What are the powerful mechanisms available for facilitation application?)	Empowerment of persons and families Self-advocacy Parent groups to elaborate common demands and propose solutions	Organization transformation Implementation of models of innovation in organizations to facilitate learning among personnel	Emphasis on human rights Emergence of interdependency Social construction of disability Emerging consensus regarding desired policy outcomes
Promoting application (What are the strategies/mechanisms to promote application?)	Parents helping other parents Information and training on rights and ways to solve personal difficulties to parent	Focus on person-centered planning Use data to assess and evaluate the person Involvement of organizations and university groups in developing empowerment approaches with persons and families	Data-based decisions in public policies Accountability Community invovlement
Increasing stakeholder involvement (Who are the major stakeholders and how can they be involved across system levels?)	Personal empowerment Family involvement in parent groups Promoting organization affiliations	Strengthen organization's role Development of networks to face and demand solutions Collaboration with university and social groups sharing the same values	Sensitize politics to include measures for implementing UNCRDP rights Implement initiatives involving community support for persons with disabilities

factors that impact policy development and its application. Table 2 provides a matrix for conducting a contextual analysis in reference to desired policy-related quality of life outcomes. In the following section, we suggest that policy application in a changing environment requires a partnership composed of policy makers, professionals, support providers, consumers, and researchers.

A Partnership Approach to Policy Application

Policy application needs to be both culturally sensitive and partnership based. In this section of the chapter, we discuss five key players and their respective roles in such a partnership: policy makers, professionals, support providers, consumers, and researchers.

Policy Makers

In addition to basing policy development on the basis of societal values, desired outcomes, and best practices, policy makers need to incorporate a 'built environment framework' into the development of public disability policy. Such a framework provides

the setting for human activity; mediates access to community resources, physically and socially; facilitates participation in community life and everyday activities and relationships; provides opportunities for self-determination; and allows individuals to build social capital, engage in competitive employment, and be more independent (Christensen & Byrne, 2014).

Professionals

Professionals play a significant role in the lives of persons with a disability. They diagnose; they treat; they recommend; and they influence attitudes, actions, and policies. Thus, professionals have both a role and a responsibility in policy application.

Professional responsibility starts with respect for the individual and is characterized by giving focused attention to the person, showing concern for the person, emphasizing the person's human and legal rights, and engaging in person-centered practices that facilitate personal well-being. Respect involves supporting

Table 3
Critical Components of Professional Responsibility

Competency Area	*Content Area*
Being aware of current international trends impacting the field	• UN Convention on the Rights of Persons with Disabilities • Quality of life concept and its application • Supports paradigm • Consumer empowerment
Being well trained in current best practices	• Best practices are based on current best evidence that is obtained from: (a) credible sources that used reliable and valid methods; and/or (b) information based on a clearly articulated and empirically supported theory or rationale • Best practices encompass: (a) the principles underlying the quality of life concept; and (b) individual support strategies composing a system of support
Acting in accordance with a code of ethics	• Justice (treating all people equitably) • Beneficence (doing good) • Autonomy (respecting the authority of every person to control actions that primarily affect him- or herself
Exercising critical thinking skills	• Analysis: to examine and evaluate component parts of a phenomenon and weigh any contradictory explanation of findings • Alignment: to place or bring processes into a logical sequence of input, throughput, and output • Synthesis: to integrate different types of information and information from multiple sources • Systems thinking: to focus on the multiple factors that affect human functioning at the micro, meso, and macrosystem levels

personal autonomy, informing people about important matters in their lives, involving people in individual supports planning and provision, providing opportunities for personal development and involvement, and assuring an individual's emotional, physical, and material well-being. As summarized in Table 3, professional responsibility is based on awareness, competence, ethics, and critical thinking skills (Schalock & Luckasson, 2014).

In addition to their professional responsibilities, many professionals need to overcome the belief that the quality of life of persons with disabilities cannot change and improve because their condition precludes development and inclusion. To overcome this misperception, it is essential to educate individuals regarding behaviorally-based QOL-related indicators reflecting growth, development, and change (Bigby et al., 2014; Reinders & Schalock, 2014). These indicators can be used to guide observations and judgments about treatment/intervention options and to develop in themselves and others the expectation that quality enhancement strategies will have a positive effect on service/support recipients.

Exemplary outcome indicators related to each of the core QOL domains are summarized in Table 4.

Support Providers

Support providers include organizations (including CBR programs), front line staff, and the families of individuals with a disability. Collectively, these support providers are increasingly reflecting the transformation of human services towards viewing the person as central, using horizontally-structured and empowered support teams, providing individualized supports that are aligned with the individual's personal goals, and focusing on personal and family outcomes (Schalock & Verdugo, 2013). To be maximally effective, support providers first need to understand the supports paradigm and the elements of a system of supports; second, to develop support strategies that are aligned with quality of life domains; and third, when organizations are involved in supports planning and provision, to align organization policies and practices to quality of life domains.

Table 4
Quality of Life Related Outcome Indicators

Quality of Life Domain	*Exemplary Outcome-Related Indicators*
Personal Development	People engage in a range of meaningful activities People try new things and have new experiences
Self-Determination	People express preferences and make choices People take part in person-centered planning and other decision-making processes
Interpersonal Relations	People experience positive and respectful interactions People are positively regarded by staff
Social Inclusion	People have a presence in the local community People have a valued role and are known in the community
Rights	People are treated with dignity and respect in all their interactions and have privacy People can physically access transport and community facilities that they would like to or need to access
Emotional Well-Being	People appear content with and comfortable in their environment People appear at ease with staff presence and support
Physical Well-Being	People live healthy lifestyles People access healthcare promptly when ill
Material Well-Being	People have their own possessions People have enough money to afford the essentials and at least some nonessentials

Table 5
A System of Supports Components, Exemplary Strategies, and Potential Outcomes

System Component	*Exemplary Strategy*	*Potential Outcomes*
Natural supports	Support networks (e.g. family, friends, colleagues, generic agencies)	Increased social inclusion, interpersonal relations, social-emotional well-being
Technology based	Assistive and information technology	Increased cognitive functioning, self-determination, and life-long learning
Education and training	Universal design for learning	Enhanced adaptive behavior and personal functioning
Environmental accommodation	Smart homes, modified transportation, job accommodation	Enhanced personal development, community living, and integrated employment
Incentives	Involvement, recognition, personal goal setting	Increased motivation and achievement
Personal strengths	Incorporating interests, skills and knowledge, and positive attitudes into support plans	Increased self-regulation, autonomy, and self-determination
Professional Services	Access to allied health services	Increased personal development, physical and behavioral health, interpersonal relations, and emotional well-being

Supports paradigm and elements of a system of supports. The supports paradigm and the provision of individualized supports have become the primary service delivery mechanism throughout much of the world (Stancliffe et al., 2016; Thompson et al., 2014). The supports paradigm has brought together the resulting practices of person-centered planning, personal development and growth opportunities, community inclusion, self-determination, empowerment, and outcomes evaluation. In the past, supports were equated to professional or organization-based services, into which a person was placed if that was considered to be the best place for him/her. The supports paradigm replaces this practice by: (a) stressing that any person-environment mismatch that results in needed supports can be addressed through the judicious use of individualized support strategies rather than focusing on "fixing the person"; and (b) shifting the focus of services and supports to bridging the gap between "what is" and "what can be"; and (c) results in approaching people on the basis of their types and intensities of support needs rather than on the basis of their limitations or diagnosis (Schalock & Luckasson, 2014).

The use of individual supports to enhance the QOL of individuals with a disability as well as to develop an outcomes-driven policy, necessitates that support providers have a clear understanding of the definition of supports, components of a system of supports, specific support strategies, and the intended outcome of the specific support strategy. Definitionally, supports are defined as resources or strategies that are designed for the person to support him/her in everyday life and that aim to promote the development, education, interests, and personal well-being of the person and to enhance their functioning. Table 5 provides a summary of the elements of a system of supports.

Support strategies aligned with QOL domains. Individualized support strategies are the actual techniques used to bridge the gap between "what is" and "what can be." As shown in Table 5, support strategies can be grouped into systems of supports. They can also be aligned with core QOL domains and anticipated effects of the support strategy such as the alignment shown in Table 6. Table 6 lists specific UNCRPD Articles aligned with each QOL domain.

Table 6a
Aligning Quality of Life Domains to Potential Support Strategies and Anticipated Effects

Quality of Life Domain	*Exemplary Support Strategies*	*Anticipated Effects*
Personal Development (UN Convention Article 24)	Facilitate personal goal setting Implement self-management, self-evaluation, self-instruction programs Build on personal strengths (e.g. practical skills, social skills, successful experiences, knowledge sharing) Maximize incentives (e.g. rewards, opportunities to be successful) Implement skill development programs Provide assistive technology (e.g. communication devices, computers, memory aides, medication dispensers, med alert monitors) Modify or accommodate environments (living, work, recreation)	Facilitates motivation and internal locus of control Enhances successful performance and increases sense of self efficacy (belief one can do it themselves) Increases personal motivation and goal setting Facilitates learning, independence, interactions, and communication Increase access and use and independence
Self-Determination (UN Convention Articles 14, 19, 21)	Allow/facilitate choice and decision making Teach self-regulation Use smart technology	Facilitates internal local of control, self-esteem, and sense of empowerment Enhances personal control
Interpersonal Relations (UN Convention Articles 23, 30)	Use communication/social media devices Involve in social skills training program Involve in peer-group (e.g. PALS, Best Buddies) Maximize family involvement Emphasize personal strengths (e.g. attitudes, skills, knowledge sharing)	Increases social engagement Increases social networks Increases perceived societal contribution

Table 6b
Aligning Quality of Life Domains to Potential Support Strategies and Anticipated Effects

Quality of Life Domain	*Exemplary Support Strategies*	*Anticipated Effects*
Social Inclusion (UN Convention Articles 8,9,18, 20, 29, 30)	Access/interface with natural supports Use social media Facilitate transportation Use prosthetics (sensory or motor devices)	Increases community access, participation, and involvement
Rights (UN Convention Articles 5, 6, 7,10,11,12, 13, 15, 22)	Advocate for full citizenship, access, due process Involve in self-advocacy Treat with respect (e.g. privacy, recognition, dignity)	Ensures equity, inclusion, and legal rights Maximizes empowerment and inclusion Reflects respect for human rights
Emotional Well-Being (UN Convention Articles 16, 17)	Provide safe and predictable environments Maximize incentives (e.g. rewards, recognition, opportunities to succeed, acknowledgements) Use positive behavioral supports Access professional services	Reduces fear and anxiety Increases motivation and satisfaction Reduces challenging behaviors and increase positive interactions Maximizes mental/ behavioral health
Physical Well-Being (UN Convention Articles 25, 26)	Provide prosthetics (i.e. sensory or motor enhancement devices) Implement nutritional programs Implement or increase involvement in exercise programs Access professional services	Increases sensory processing and physical mobility Maintains weight control and encourage proper and balanced nutrition Enhances human functioning and reduce negative effects of obesity and/or inactivity Maintains or improves medical/physical condition
Material Well-Being (UN Convention Articles 27, 28)	Involve in supported employment program Provide paid sheltered workshop employment Network with generic employers Enroll in vocational training program Participate as a volunteer	Increases economic self-sufficiency and sense of accomplishment Increases job-related skills and behaviors Increases sense of contribution and purpose

The delivery of individualized supports needs to be done in a rational way. Depending on the circumstances, some type of individual supports plan is developed for the person and implemented by one or more support providers. As commonly employed, an individual support plan includes: (a) an organizing framework (e.g. life activity areas, human functioning domains, quality of life domains); (b) prioritized support areas based on what is important to and for the individual; (c) support strategies reflecting components of a system of supports; (d) support objective that integrate the specific strategy used and the intended result of that strategy; and (e) personal outcome categories (e.g. life activity areas, human functioning dimensions, or quality of life domains).

Ten best practice guidelines have evolved regarding the development and implementation of individual support plans. These 10 are (Herpes et al., 2016; Schalock & Luckasson, 2014):

(1) the client and the person's family and support staff who know the individual well are involved in the plan's development, implementation, monitoring, and evaluation;
(2) priority is given to those outcome areas that reflect the person's goals and relevant needed supports;
(3) an outcomes-focused framework is used to aggregate support strategies and objectives to person-referenced outcomes that are important to or for the individual;
(4) support objectives are referenced to specific support strategies rather than person-specific attitudes or behaviors;
(5) the plan is implemented by multiple entities, including the service recipient, one or more family members, front line staff, and a case manager/supports coordinator;
(6) the plan should be user friendly and easy to communicate to facilitate effective implementation;
(7) monitoring of the plan involves determining the status of support objectives;
(8) evaluation of the plan involves the assessment of personal outcomes;
(9) the plan should be modified when the individual's goals change significantly; and

(10) the plan should be modified when the support needs of the person change significantly (e.g. changes in major life areas, such as health, education, residence, or employment status).

Organization policies and practices aligned with QOL domains. Internationally, a variety of organizations are providing services and supports to persons with disabilities. Some of these are NGOs, some are public not-for-profit entities, and some are for-profit corporations. Within a quality of life outcomes-focused framework, to maximize personal outcomes these organizations need to align their policies and practices to the supports paradigm, the quality of life concept, and outcomes evaluation. Table 7 summarizes a number of quality improvement strategies that will result in a better alignment of organization policies and practices to each QOL domain.

The information presented in the first column of Table 7 is important and should not be overlooked. The reader will find in column 1 a listing, based on the work of Claes et al. (2016) and Verdugo et al. (2012), of the UNCRPD Articles associated with each QOL domain. This identification and association will assist jurisdictions that may have made changes in their policies related to implementing the Convention, but have yet to show significant progress in changing their actual practices (Mittler, 2015; Schalock & Keith, 2016).

Consumers

An essential member of the partnership is the consumer. Although their critical and essential role is often overlooked, persons with a disability are increasingly becoming more actively involved in the development, provision, and evaluation of individual supports. This increase is due to a number of factors including the increased rights of persons with a disability, the inclusion in service delivery policies and practices of the QOL concept, and the findings that people with a disability have competencies and capabilities that are frequently ignored or stymied (Keith & Schalock, 2016; Nussbaum, 2011; Mosteret, 2016).

What does it mean for consumers to be more active members of a support team? From a systems perspective, it means that the individual is involved in the input, throughput, and output

Table 7a
Aligning QOL Domains to Organization Policies and Practices

Quality of Life Domain	*Exemplary Quality Improvement Strategies*
Personal Development (UN Convention Article 24)	Implement staff training programs in Person-Centered Planning that include developing cognitive processes related to self-management, instruction, goal setting, evaluation, and reward Expand use of assistive technology, including communication devices, memory aides, problem-solving apps, medical monitoring devices Develop 'bridges to the community' to provide personal development opportunities Sensitize staff to the importance of building on the client's personal strengths and maximizing incentives
Self-Determination (UN Convention Articles 14, 19, 21)	Implement staff training programs that focus on choice making, decision making, and self-regulation Expand use of smart technology that permits personal control
Interpersonal Relations (UN Convention Articles 23, 30)	Increase use of social media techniques and devices Develop self-advocacy and peer group organizations Implement social skills training programs Involve families to maximize their involvement and membership in Support Teams Implement peer counseling and teaching programs
Social Inclusion (UN Convention Articles 8, 9, 18, 20, 29, 30)	Increase use of social media Implement transportation voucher system Use sensory/motor aides (i.e. prosthetics) to facilitate access and participation Develop 'bridges to the community' to maximize social inclusion and participation Encourage self help group membership

Table 7b
Aligning QOL Domains to Organization Policies and Practices

Quality of Life Domain	*Exemplary Quality Improvement Strategies*
Rights (UN Convention Articles 5, 6, 7, 10, 11, 12, 13, 15, 22)	Establish and support self-advocacy groups and group membership Develop an ombudsman position Operationalize protection and advocacy activities
Emotional Well-Being (UN Convention Articles 16, 17)	Establish regular routines that reflect the 'natural rhythm of life' Provide maximum staff continuity Provide staff training in developing and implementing positive behavior supports Develop client-referenced incentive programs Access mental/behavioral health professionals when necessary
Physical Well-Being (UN Convention Articles 25, 26)	Contract with Occupational and/or Physical Therapists to procure and use prosthetics (sensory/motor devices) Implement video demos, electronic apps, or classes in balanced, wholesome eating and food preparation Join Special Olympics or similar athletic/ sports clubs Set up exercise programs in living and work environments
Material Well-Being (UN Convention Articles 27, 28)	Establish or expand supported employment programs Transform shelter workshop program to paid employment center Outsource employment programs Implement a volunteer services outreach program

Table 8a
Quality of Life Domains, Their Primary Focus,
And Activities or Questions to Frame a Dialog

Quality of Life Domain	*Primary Focus*	*Activities or Questions To Frame a Dialog*
Personal Development (UN Convention Article 24)	Deals with your education (including lifelong learning) and personal competence (including learning and demonstrating skills).	Learning about the things you are interested in Learning skills to become more independent Being able to take care of yourself Being able to follow your own interests Having access to information
Self-Determination (UN Convention Articles 14, 19, 21)	Deals with your personal goals and objectives, decision making, and making your own choices.	Making your own choices Deciding yourself what to wear Expressing your own opinion Acting on your own personal goals and aspirations
Interpersonal Relations (UN Convention Articles 23, 30)	Deals with your family, friends, social network, and the supports you receive from others.	The contacts you have or the time you spend with family and/or friends The respect or feedback you receive from family and friends The support you get from family and friends The respect you receive from others
Social Inclusion (UN Convention Articles 8, 9, 18, 20, 29, 30)	Deals with your community integration and participation, the community roles that you play, and the social supports you receive.	The community activities you participate in The contacts you have with people in your neighborhood The help you get from people living in the community The number of memberships you have in community organizations

Table 8b
Quality of Life Domains, Their Primary Focus,
And Activities or Questions to Frame a Dialog

Quality of Life Domain	*Primary Focus*	*Activities or Questions To Frame a Dialog*
Rights (UN Convention Articles 5, 6, 7, 10, 11, 12, 13, 15, 22)	Deals with both your human rights (respect, dignity, equality) and your legal rights (citizenship, access, and fair treatment).	Your right to privacy and a private life How people around you treat you The opportunity you have to say what you think and being listened to The right to have a pet Having a key to your house Being able to vote
Emotional Well-Being (UN Convention Articles 16, 17)	Deals with your contentment, self-concept, and lack of stress in your life.	How you express your feelings Are there elements of danger in the environment where you spend most of your time Do you worry or have serious concerns in some matters? In what matters? How stable and predictable is your environment?
Physical Well-Being (UN Convention Articles 25, 26)	Deals with your health and health care, nutrition, self-care skills, mobility, and recreation.	Do have the energy to participate in physical activities? Do you limit how much you eat so you do not gain weight? Do you participate in recreation and leisure activities and/or sports?
Material Well-Being (UN Convention Articles 27, 28)	Deals with your financial status, employment status, living arrangements, and personal possessions	What is your monthly income? Do you have personal possessions that are important to you? Do you have a paid job? Are there things or goods that you cannot afford to buy because of lack of money?

phases of support planning and implementation. More specifically, during the input phase, a dialog should occur during which the individual expresses their personal goals and support needs. At the process stage, the individual is involved in developing, implementing, and monitoring his/her support plan. And at the output phase, the individual is involved in the assessment and evaluation of quality of life-related outcomes. Key aspects of these roles are described next.

Input phase A transformation is occurring in the purpose and content of individual support plans. The transformation involves: (a) distinguishing between a service contract that contains all of the legal and regulatory requirements and an individual supports plan that aligns identified and desired personal goals and assessed support needs to specific elements of a system of supports and identified and desired personal outcomes; (b) focusing on the whole person rather the person's medical, behavioral, or psychological deficits only; and (c) using a horizontally structured support team that includes the consumer in the planning, development, implementation, and evaluation of individualized support strategies (Herpes et al., 2016; Schalock & Luckasson, 2014).

Obtaining information about the individual's personal goals is an essential part of this transformation. As outlined in Table 8, a dialog can be held with the person (or the individual's spokesperson) based on their goals related to each quality of life domain. The utility of Table 8 is that it aligns UNCRPD articles with the respective QOL domain, describes in user-friendly language the primary focus of each QOL domain, and provides a number of activities or questions around which a dialog can be had.

Process phase. As a member of the support team, the consumer is involved in the development of his/her supports plan that is based in large part on his/her personal goals, assessed support needs, and individualized support strategies. An essential question to ask at this point is, "What happens next?" Is the person and other members of the support team, such as family members and front line staff, involved in the plan's implementation?

A significant by-product of transformational thinking is the realization that the effectiveness of the individual supports plan is reduced because it is often too long and too complex, developed by the few, and implemented by even fewer. As thinking shifts more and more to the person as central, streamlining processes and products, and involving key stakeholders in the supports planning and implementation process, the format of the individual plan is changing. Throughout many national and international jurisdictions, we are seeing the development of user friendly support plan formats such as those listed below (Schalock & Luckasson, 2014):

- *My Support Plan*: a 1-2 page individual supports plan that lists those goals and support needs that are important to the person. This plan also lists the support strategies and the entity, including the individual, responsible for implementing the specific support objectives.
- *Plan-at-a Glance*: A 1-page sheet that lists the learning objectives in brief, concise language and explains how they can be supported in the typical environment.
- *Family Role in the Individual's Support Plan*: a 1-to 2-page summary that provides parents/family members with a complete picture of the individual's personal goals and assessed support needs, support strategies, and the specific support objectives for which the family is responsible.
- *Front Line Staff Action Plan*: a 1-to 2-page summary that provides support staff with a complete picture of the individual's personal goals and assessed support needs, support strategies, and the specific support strategies for which they are responsible.

Output phase. Consistent with the focus of this chapter on outcomes-driven policy and its application, we advocate that in reference to the output phase, consumers are involved in the assessment of personal, quality of life-related outcomes. As discussed by Gomez and Verdugo (2016) and Schalock et al. (2016), the current approach to the measurement of QOL-related personal outcomes is characterized by its multidimensional nature, the coexistence of universal and culture-bound properties, the use of methodological pluralism involving self-report and report-of-others, and the importance of involving the consumer. Table 4

provided a template for using QOL-outcome indicators as items in a QOL assessment instrument. Specific examples of QOL assessment instruments can be found in Gomez and Verdugo (2016). The assessment of personal outcomes has high stakes for consumers, organizations, and service delivery systems. Therefore, outcome evaluation must conform to a number of best practice guidelines in test development and assessment. As discussed by Gomez and Verdugo (2016) and Verdugo et al. (2005), these involve: a well-formulated and validated conceptual model, use of culturally sensitive indicators, a Likert scale scoring metric, established psychometric properties, standardized administration procedures, and parallel versions of the scale (one version for self-report, and a parallel version for report-of-others for those who cannot/ do not self-report).

QOL-related outcomes can be used for multiple purposes that include monitoring and reporting, establishing quality improvement strategies, and conducting research. At the individual level, QOL scores can be used to provide feedback to individuals regarding their status on the domains composing a life of quality. Such feedback establishes an expectation that change can occur, confirms that the organization serving the person is committed to a holistic approach to the individual, and evaluates whether personal and organization-level quality improvement strategies have made a difference in their lives.

Researchers

Those involved in research are also key members of the partnership. Research has historically played a major role in how we conceptualize, measure, and apply the QOL concept. Specifically, research has validated the eight first-order QOL domains; established a measurement framework based on best practices; identified some of the factors (i.e., moderator and mediator variables) influencing QOL-related outcomes; suggested application guidelines related to personal involvement, individualized supports, and personal growth opportunities; and provided an empirical basis for the following definition of individual QOL that can be used as a basis for QOL research.

> Quality of life is a multidimensional phenomenon composed of core domains that constitute personal well-being. These domains are influenced by personal characteristics and environmental factors that act as moderators or mediators. One's quality of life can be enhanced through quality enhancement strategies that encompass personal involvement, individualized supports, and personal growth opportunities.

In reference to this chapter's focus on policy development and its application, future research efforts will likely emphasize outcomes evaluation and establishing evidence-based practices. In that regard, we suggest the following five guidelines that are congruent with an outcomes approach to policy development and a quality of life application focus.

1. Approach the conceptualization and measurement of QOL from a multidimensional perspective that reflects the etic (i.e., universal) properties of the core QOL domains and the emic (i.e. culture-bound) properties of QOL indicators.
2. Use personal, QOL-related outcomes as dependent variables in multivariate research designs.
3. Evaluate the generalizability of the QOL concept and its application across geographical regions, cultural and language groups, and human service populations (e.g. special education, aged, mental and behavioral health, chemical dependency).
4. Determine the factors (i.e. moderator and mediator variables) that affect QOL outcomes.
5. Involve individuals with disabilities, their families, and support providers in research endeavors.

Developing and Applying Policy in a Changing Environment

The proposed policy development framework discussed in this chapter incorporates outcomes-driven policy formulation with a quality of life-focused application. Successfully developing and applying this approach requires an understanding of its empirical basis, the need to approach its development and application systematically, and the wisdom of being sensitive to contextual issues.

Empirical Basis.

The framework discussed in this chapter is consistent with three significant findings reported in the literature. The first finding relates to the analysis of national and international disability policy statutes and documents (Shogren et al., 2015). This analysis identified three specific policy goals: those related to human dignity and autonomy, human endeavor, and human engagement. In addition, the analysis identified specific personal outcome domains associated with each goal. Personal outcomes associated with human dignity and autonomy were self-determination and full citizenship; for human endeavor, education/life-long learning, productivity, and well-being; and for human engagement, inclusion in society and the community, and human relationships. Thus, we see an emerging consensus regarding desired policy goals (see Table 1). Furthermore, these goals and related outcomes are aligned with personal outcome domains and associated indicators that parallel the eight core QOL domains discussed throughout this chapter (see Table 4). The respective indicator can be used to assess personal outcomes that can be aggregated at the organization, system, and/or national level to evaluate the effects of the respective disability policy goal.

The second finding is based on the work of Verdugo et al. (2012), Bradley et al. (2016), and Claes et al. (2016). As shown by these authors, QOL domains can provide a framework for implementing UNCRPD articles. Although the Convention does not articulate means for implementation that would ensure an enhanced QOL, the Convention articles can be operationalized through outcome-focused policies related to: (a) person-centered planning with a focus on QOL-related domains and personal outcomes; (b) publication of provider profiles detailing quality-related outcomes and quality improvement activities; and (c) a program of individualized supports designed to enhance QOL-related personal outcomes and individual rights.

The third finding is that environment can be built that enhance desired, QOL-related outcomes (Christensen & Byrne, 2014; Reinders & Schalock, 2014; Schalock et al., 2016). These environments provide the setting for human activity; mediate access to community resources, physically and socially; facilitate participation in community life and everyday activities and

relationships; provide opportunities for self-determination; and allow individuals to build social capital, engage in competitive employment, and be more independent.

Systematic Approach.

The empirical basis just described indicates that there is both a conceptual and values-based foundation for outcomes-driven policy development and its QOL-focused application in LAMI countries and elsewhere. To supplement that foundation, we suggest five important steps in developing and applying policy in a changing environment. First, establish partnerships among policy makers, professionals, support providers, consumers, and researchers. This will ensure participation and collaborative actions that maximize synergy and success. The era of compartmentalization and silos is over. We can't afford it, and people with disabilities and their families are tired of waiting.

Second, advocate for policies that specify desired and relevant outcomes that are person-referenced, family-related, and/or societal focused (see Table 1). In addition, these policies should be value-based and specify best practices for their implementation. Best practices include those based on person-centered planning, the quality of life concept, the supports paradigm, and outcomes evaluation.

Third, advance the use of contextual analysis that policy makers and support providers can employ to facilitate policy development , policy application, and organization/systems change. As reflected in Table 2, contextual analysis facilitates adoption and change by identifying the factors that hinder change, the strategies and mechanisms for promoting and facilitating change, and the stakeholders who are most likely to bring change about.

Fourth, align critical aspects of the application framework. Earlier in the chapter, for example, we discussed the importance of: (a) aligning UNCRPD articles and specific QOL domains (see Tables 6 and 7); and (b) aligning QOL domains to activities or questions to frame a dialog with the consumer (Table 8), aligning potential support strategies and anticipated effects (Table 6), and aligning organization policies and practices to QOL domains (Table 7). Without such alignment, many organizations and

systems will continue to not only encounter obstacles to implementing the UN Convention articles, but also to be unresponsive, ineffective, and inefficient.

Fifth, policy makers and regulators need to understand the distinction between summative and formative evaluation. Summative evaluation is used for accountability purposes, whereas formative evaluation is used for program improvement. Each of these two purposes is associated with a different set of questions to be answered and methods to be used. Additionally, a summative evaluation (such as that required for licensure or accreditation) typically produces more anxiety among participating stakeholders than a formative evaluation, which usually generates excitement due to its learning and development focus. We suggest that policy development and its application should focus on formative evaluation that will enhance policy application, facilitate programmatic transformation, and improve personal, family, and societal outcomes.

Contextual Issues.

We are living in a changing environment characterized by a transformed understanding of—and approach to—persons with a disability. Mental models and public attitudes are shifting to a social-ecological model of disability (rather than defectology), social/community inclusion (rather than segregation), human and legal rights (rather than denial of the rights of persons with disabilities), self-determination (rather than control), and personal development and well-being (rather than stagnation).

Policy development and its application need to reflect not only this transformation but also the contextual environment of the county, region, or jurisdiction. For example, we recognize that the five steps discussed above in reference to systematic change must be contextualized to reflect potential differences across countries and cultures (World Health Association, 2011). In reference to policy development, for example, policy-related outcome domains related to outcomes-driven policy disability goals may need to focus initially on those outcomes most needed or significantly lacking in a particular society. Specifically, human dignity and autonomy as a disability goal might emphasize full citizenship,

whereas human endeavor emphasizes well-being, and human engagement focuses on inclusion in society and the community.

In reference to organization and systems transformation, social welfare agencies, in partnership with professionals and other NGOs, may work jointly to support health, education, and social welfare staff in providing assistance, services, and supports to people with disabilities and their families. In addition, organization and systems transformation will be reflected through social entrepreneurship activities and entities that result in creating social value by improving peoples' lives, building community, and improving society.

In regard to professional education and support provider development, the agenda might well differ, depending on the country and its current primary service delivery model. For example, in countries where the CBR model is used, the focus will likely be on providing education and development to health, education, and social welfare staff who already work in the community but often lack confidence or motivation to extend their skills to people with disabilities and their families. In developed countries wherein direct support staff provide care, supervision, and supports, the focus will more likely be on team development and competency-based training (Buntinx, 2008).

10
INTERNATIONAL ASPECTS – FAMILIES IN ACTION

Gare Fabila

It would not be until we have created and maintained decent conditions for every human being. Until they are recognised and accepted as a common obligation for each one of men and countries. It would not be until then that with a certain degree of justification we may speak about a civilised man.

ALBERT EINSTEIN, 1945

INTRODUCTION

It has been a long and difficult road for persons with disabilities and their families to have their rights recognised. Struggle against indifference, discrimination, prejudices have been common all over the world. But due to the joint pressure of families and some outstanding social leaders the legal framework has been emerging. Many treaties, declarations, celebrating years declared by the United Nations have been paving the way to reach a comprehensive inclusion of persons with disabilities all over the World into society. Finally with the Convention on the Rights of Persons with Disabilities of 2006, a comprehensive human rights treaty, established the rules and obligations amongst governments to avoid making them excluded from society and be able to enjoy their full rights as citizens.

DISCRIMINATION AGAINST PERSONS WITH DISABILITIES

Humanity has been cruel to those who are different. There are many examples: in ancient Greece babies born with any kind of malformation or disability were thrown down Mount Taygetus. In the Middle Ages small walled-cities were built to segregate blind people. Epilepsy was thought as a demoniac possession, and now-a-days it is still considered so in some places. Once travelling through the south of Mexico we found a young girl begging for a

penny; when we asked her what she needed it for she said that it was to purchase a medicine for a "malady attack", because she could not attend school for she was "possessed by the devil".

We were once making a field work on 16 families for the United Nations when we met an African father who had a young son with intellectual disability; he told us that in some parts of his country there were violent reactions against him: they threw stones or sticks and shouted insults … this is by the end of the twentieth century, and still it happens.

Now-a-days it is a usual state of the art technology to discriminate if a foetus is being formed with Down syndrome and this can lead and often does to the termination of pregnancy. While this happens chiefly in developed countries in a lesser way it occurs in developing countries, particularly amongst the wealthiest. (see the chapter Some questions about Down syndrome). According to a recent article (Natoli et al. 2012) based on data gathered across 15 years in different hospitals and clinics in the United States (there are no reliable figures for Mexico or Latin America) it is estimated that the percentage of pregnancies terminated with Ds diagnosis is 67%, and though there is a significant reduction from the figure of 90% in the nineties it is still very high. In the United Kingdom figures for termination rates are 75% (Buckley 2008). What these data suggest is that parents are afraid and do not know what to do; they cannot imagine being able to cope so they take this solution.

In spite of all the advances of Society many barriers persist, physical, social and cultural; myths and discrimination which segregate people with disabilities from a good quality of life. There is denial from health services to disabled persons and their families; rejecting and underestimating their human value. There are still schools that discriminate those who are in need of a greater support, and if they accept them they then face the problem of teachers with no information on how to facilitate their learning or even the disposition to do so. In the curricula of schools for Professional Teacher Education little or nothing is about teaching persons with disabilities or special needs. Some schools and teachers use the rhetoric of inclusive education but the only thing they do is to accept in their classrooms people with disabilities who remain excluded from the learning processes, without the proper

attention to lead them to successful learning or providing the necessary support.

Families in action

The road for persons with disability and their families has been weary: difficult, segregated, full of pain, withstanding discriminations and all sort of imposed barriers. Families who have not been willing to seclude their children in psychiatric institutions with a restricted and often terrible kind of life – the only alternative not so long ago – without education or elementary human rights ignored the advice of doctors and decided to assume a spirit of fight so they would enjoy their full rights and all the possible opportunities within their own limitations and Society's.

This has been a continuous struggle, misfortunes and achievements where conformism has no place; where families became promoters to change Society in the direction of our aspirations and that of our children.

The role of the United Nations

In 2011, The World Health Organisation made a study that concludes that about 10% of the total population in the World has some kind of disability, with individual percentages of prevalence in the different countries with variations from 4% to 20%. This would mean that in our country around 12,000,000 Mexicans would have some kind of disability. According to the US Agency for International Development USAID, the figure is closer to 20%, meaning that the number would be double, 24,000,000.

With these numbers in mind, governments should meditate on the urgent need to take over their responsibility and provide the necessary means to provide a decent quality of life for that population, considering in addition that the elderly, who are growing in numbers all over the world, develop disabilities.

By the middle of last century, on the 24th of October, 1945 the United Nations was formed with the aim of peacekeeping and security to avoid another war and besides to aim at promoting economic development, humanitarian assistance and human rights. Since its foundation many Treaties and Conventions have been signed. Conferences held and Commemorative Years celebrated;

some treaties have a binding character that has the same status as internal laws of signing countries, therefore providing a framework, which imposes obligations to improve the conditions of living for people with disabilities.

These actions have had mixed success: some countries have made changes in their policies, at least partially; others have plainly ignored them, as demonstrated by the periodical evaluations.

Then the Universal Declaration of Human Rights was adopted by the General Assembly on 10 December 1948 as a result of the experience of the Second World War and manifests the equality of all human beings. It is a marvellous document, at least as a common ideal to which every country should aspire. The following is a transcription from the second article:

"Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty".

The Declaration establishes that every human being is born free and equal in dignity and rights, without any distinction, and everyone has the right to be protected against any kind of discrimination.

These concepts have been elaborated in other documents such as (United Nations Enable 2004),

- The Declaration on the Rights of Mentally Retarded Persons, 1971
- The Declaration on the Rights of Disabled Persons, 1975
- The International Covenant on Civil and Political Rights, 1976
- The International Covenant on Economic, Social and Cultural Rights, 1976
- The International Year of Disabled Persons, 1981
- The International Convention on Work, 1983
- The Convention on the Rights of the Child, 1989

- The World Programme of Action Concerning Disabled Persons, 1982 – 1992
- The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993
- The International Year of the Family, 1994

And The Convention on the Rights of Persons with Disabilities that was adopted on 13 December 2006 at the United Nations Headquarters in New York. It is the first comprehensive human rights treaty of the 21st century and is the first human rights convention to be open for signature by regional integration organizations (United Nations 2006).

Each one of them has been paving the way to reach a comprehensive inclusion of persons with disabilities all over the World into society. The rules and obligations are clearly established amongst governments, society, families and disabled people themselves in this struggle to avoid making them being excluded from society and to be able to enjoy their full rights as citizens.

INEXACTNESS OF DATA

One of the first limitations to put into practice this framework is the knowledge of the real magnitude of the problem, due to inexactness of data of population census. This is a worldwide problem, in some countries due to the inefficiency of the recording processes in others to the intentional hiding of information. For example in the Mexico 2010 census of population (INEGI, 2010) it is said that the total population with any disability (walk and move, see, hear, talk or communicate, self-care, attention deficit and mental) was approximately 5% of the total population whereas United Nations data records a considerable larger figure (World Health Organisation, 2011)

We know we need accurate information about several aspects: how many of us are there, where do we live, what are the real living conditions, how good are services, what is the real budget allocated to improve quality of life. What are we doing in countries like Mexico for people with disabilities, in large cities as well as in small towns and rural areas, marginalised populations such as those of mixed ethnicity? We need that information to

know what the real advances we are making, if any, to help persons with disabilities and their families and to consider every kind of disability, including the most severe that require more support from government as well as from society. There is also mental illness whose existence is usually denied particularly when other disabilities are present. In summary, we need to know what the quality of life in Mexico is at the beginning of the 21st century as compared to other developing countries.

It is intolerable that inequality and social injustice continues to prevail and the little advances tend to be limited to large cities. We cannot tolerate that the disabled and their families receive the little they have as charity and not as a right.

This situation required the Secretary General of the United Nations to designate a Special Rapporteur to inform the Commission for Social Development on the application of The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations (1993). In 1994 Bengt Lindqvist from Sweden was appointed initially for three years and then twice extended, in 1997 and in 2000. The task of Lindqvist was to monitor the implementation and offer his point of view.

"EVERY PERSON WITH DISABILITY MEANS EACH AND EVERYONE"

Amongst the findings of Lindqvist was the fact that disabilities were not considered among mainstream technical cooperation issues amongst Nations thus he recommended that the United Nations Development Programme (UNDP) and the World Bank integrate this concept as a condition of financing their projects. Inappropriate support was also found in education, employment, physical environment and information and communications technologies. Government monitoring was poor or non-existent. A basic aspect was that the Rules were not binding and were vague as far as children, gender, housing and refugees were concerned.

Lindqvist emphatically pointed out those changes necessary to be made in the world meant for everyone: "Every person with disability means each and everyone".

This should have been obvious, as already stated in the United Nations, but has not occurred. In spite of the large effort made jointly by governmental teams, society and above all the inclusion of families in the promotion and development of this

Treaty and the promotion of many coordinated actions around the World for the first time in history, the results fell short of achieving the necessary solutions.

What was achieved during the nineties and the early years of the present century was to build a common vision all over the world and raise consciousness about the need for change that has to be made in order that each person with disability and their families have their rights recognised just as much in rural areas as well as in the cities, and that should include every form of disability. Although practical implementation was not nearly fully achieved given the magnitude of the problem, at least governments, people with disabilities and their families and society began working hand-in-hand. The magnitude of the problem clearly became apparent in developing countries where it was found that 70% of all the people with any form of disability lived.

Advances were due mainly by the motivation of leaders during the period when the declarations were made, beginning with those involved on the policies of the UN who were for the first time selected from persons who either had a disability or were fathers or mothers of someone who had a disability. They represented all existing disabilities and that made all the difference.

Bengt Lidqvist himself was blind. He had been Minister for Social Development in his own country of Sweden, and when appointed he moved and prepared the whole world. During the nine years of his mandate he travelled extensively to publicize the Standard Rules and the rights of persons with disabilities. He evaluated all countries to determine the prevailing conditions and had interviews with presidents so they heard at first hand about the declarations of the United Nations and the needs involved so that governments could offer solutions on a real and practical basis.

He came to Mexico five times where he worked alongside the government, society and the organisations of people with disabilities and their families. He had interviews with the President, several members of the Cabinet, and the main organisations of people with disability, university students, and the media. He participated in conferences, seminars and workshops.

He wrote a book summarising the situation in the World and objectively reflected the seriousness of the global problem,

more than trying to criticise. This book has the numbers governments rather forget, and described how the majority of human beings lived in inhuman conditions, struggling against all kind of barriers, physical, social and discriminatory, and above all the indifference of society. This meant and still means that millions of children, young persons, adults and the elderly are deprived of their elementary rights and this manifested in social injustice mainly in poor countries but in some rich ones as well.

The Convention on the Rights of Persons with Disabilities

As a result of this work the community of organisations for the disabled developed a common vision with which they have pressed governments and society to make the necessary changes. In the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, held in Durban, South Africa, from 31 August to 8 September 2001 (United Nations Durban 2002), Lindqvist took the proposal of Mexico to elaborate a full and comprehensive document on the rights of the disabled. The resultant was a proposal 56/168 known as Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities (United Nations 2001), which was approved on the 88th plenary meeting, held on 19 December 2001.

Hundreds of countries and civil organisations adhered to this proposal held in the United Nations Headquarters, which had representatives from many organisations of persons with disability. Thousands of items of mail were received; letters and phone calls from all over the World. This led to the generation of an unprecedented movement, the biggest in all the history of the United Nations, and thus the first Binding Treaty on human rights was signed. It has higher hierarchy and authority than national legislations.

The work has not stopped. Bengt Lindqvist (1994-2002) was succeeded by Ms. Sheikha Hissa Khalifa bin Ahmed al-Thani, from Qatar (2003-2005) and presently the Special Rapporteur is Mr. Sr. Shuaib Chalklen from South Africa (2009), all distinguished social leaders in favour people with disabilities.

In most countries changes are being undertaken, some true though some others merely cosmetic. However there are

committees at national and international levels monitoring the fulfilment and harmonisation of internal legislation, its application and creation of public policies according to the articles of the Convention and the needs of each country along with the benefits for the disabled population and their families. This is a remarkable advance in such a short time.

There are still countries lagging behind without true development and large gaps between the rich and the poor particularly in developing countries, and sadly even among people with disabilities and their organisations, which is a sort of discrimination itself. The least protected are those with multiple disabilities, the elderly, many those of diverse ethnic background, immigrants and person with mental disorders.

The struggle in our Latin American Environment

Our region has a vast heterogeneity, with extreme wealth coexisting with extreme poverty. There is, it is true, wealthy families often taking the place of governments in funding necessary social needs. That is why we emphasise that public policies emanated from the United Nations Convention should empower persons with disabilities – as well as their families – by listening to their voices and providing the means for them to be able to support themselves and their children.

We need a Society willing to help a family from the very moment of the detection of a disability in the baby in the womb and not to destroy it but to give all necessary support in order that he or she may have the best opportunities, being aware that everyone has the same rights as any other Mexican (or other) national.

There needs to be a willingness to support the development of each child by providing an information system easily accessible in every health centre, regional or municipal, to avoid the present journey frequently required to go from one to the other carrying a baby in arms seeking the support they need. Guiding, supporting and accompanying help, is required while being aware of the groups of self-support, the national movements for different disabilities, the different Conventions, international treaties which give them rights and that governments have committed to fulfil.

The author of this chapter, a mother of a child with multiple disabilities, began her journey in 1970. She has witnessed many changes, most positive yet slow, unequal, encountering that the difference lies in families with high spirits who have continually been pressing Society to change and develop in order to meet pressing needs.

This book talks of the role of grandparents, who participate in the emotional and sometimes painful process of watching their loved ones struggle, for on one hand they have involvement with their grandchild and on the other involvement with their own child, and sometimes the support they might require is unattainable. It would be desirable to have support groups among grandparents, since it has been observed that they may play a crucial role, as mentioned in field research quoted in a previous chapter (Cunningham 2006).

The richness demonstrated in the grandma who accompanies her grandchild in finding his or her own way or the voice of the grandparents reinforcing the parents in working towards the success of their grandchild, even before it is born, can be uplifting. We have written this book to share our thoughts, our information and above all our experiences to enrich our Latin American milieu; to empower parents and grandparents with information so one day everyone with a disability can enjoy a better quality of life, and "Every person with disability means each and everyone", as Bengt Lindqvist put it.

And, in order that inclusion is not just rhetoric, we need better trained general practitioners, paediatricians, neurologists, psychologists, social workers and teachers of special education as well as regular therapists in the many areas, so the child progresses according to the best of his or her abilities and is socially included from the early stages of development. Fortunately this is beginning to happen, particularly on the past three decades, though we are still far from that practiced in more economically advanced societies.

THE DIFFERENT STAGES

Mexico has made advances thanks to the indefatigable work of social leaders who took on the responsibility of trying to improve the conditions of people with disabilities. Now-a-days many

private as well as state schools have begun inclusion programmes with variable degrees of success but have meagre resources. There remains much more to be done.

To begin with the common ground was dissatisfied families who have struggled to achieve a better quality of life for their children. Families have joined other families enlarging the circle to mobilising governments and society. Changes begun small have become large and have worldwide implications.

In advanced societies private and public institutions developed an educational model that has been evolving from purely medical assistance to rehabilitation and finally education and inclusion centred on increasing the abilities of people with disabilities. Many things are possible when proper coordination is established among the different actors.

But the problem is global, for the job is not complete anywhere, so a social model comprising all aspects should be sought. That began to happen when persons with disability from all over the world convened an international movement. Bengt Lindqvist promoted the idea that our movement should not be limited to education or health, but for all human rights, and those should be exactly the same for everyone, with or without disabilities. This was taken to the High Commissioners of Human Rights, of the World Health Organisation and of the International Labour Organisation, which in turn gave rise to the Convention on the Rights of Persons with Disabilities.

It is still necessary to put this declarations into practice for some groups have not advanced as much as others, even though all of them were covered by the Convention. We should not step back until there is social justice for everybody. As Diane Richler, former President of Inclusion International, said "We ought not to allow having elites between people with disabilities, where some have services that others lack". Some regions are lagging behind, such as Africa and parts of Asia, where attempts have been made but little has happened.

And since the purpose of this book is to contribute to the empowerment of families by offering them information we wish to end this chapter with some of the objectives we consider should be promoted:

Families should inform themselves, study and develop their capacities as leaders to have influence on the changes that are still to be made.

It is necessary to reflect on specific goals for the public policies based on the rights clearly established in the Convention, to strengthen society.

One of us (GF) cites a phrase that reflects more that 45 years of work with families who have a child with some disability. All of them participated in promoting family union as the most important basis for our Eduardo – our son – by giving love, fellowship and solidarity, and though he is no longer with us he has left his trace in a new sense of and for our lives.

And this phrase, from Ann Wallace, social worker, summarises all (Thompson, Richard H. (Editor) (2009):

"I work collaboratively with families not only because it's the right way to do things, but because it's the most enjoyable, energizing and satisfying way to provide services".

Part Four

ACHIEVING THE FUTURE

All children are born with different potentials for their development. The role of parents, educators and the community is to make sure that nothing happens that limits it, and that everything is done to promote it (Cunningham, 2006). In this sense, people with Down syndrome are nothing different from others: they have aspirations and dreams. In order to let them achieve they, support and encouragement are crucial.

In this part of the book we see the stories of five young people from places as diverse as the United States, Argentina, Mexico, Singapore and the Netherlands that have managed to stand out in their fields, but above all have led a life that has made them and their families happy: if they could so you shall. The section concludes with a photographic essay that shows scenes from the daily life of young adults with Down syndrome who mix with their peers and friends and perform the activities of anyone of their age: sports, painting, dancing, playing with your companions and fall in love. The author narrates his approach - fearful at first and then warm and enthusiastic - towards this human group.

11
TESTIMONIES:
"IF I COULD SO YOU SHALL"

Let nothing stand in your way of fulfilling your dreams
DYLAN KUEHL

We are all down, we are Miguel Tomasín
LOS REYNOLS

I am a working girl with Down syndrome
NATALIA CAROLINA LÓPEZ

It is not a matter of adapting the world to them but rather adapting them to the world they will live in
ALEJANDRA ZEPEDA

To speak up so others can understand our feelings and dreams
JASPREET KOUR SEKHON

But yes, VIP's always have others write for them! and yet they know what they are talking about. And so do I!
DAVID DE GRAAF

INTRODUCTION

Variability is large amongst people with Down syndrome: a few gain university qualifications and have full time employment and independent lives, others require more support and their academic achievements may not be so large but have other skills instead, perhaps larger. All have their place in society and have much to offer. The question is not of disabilities but of abilities, as one of our stories tells.

And since it is impossible to know how life is going to be for our baby the wisest thing to do is to provide as much love and support and medical care as we can so when growing he or she will have the best possible quality of life and above all the one he or

she chooses.

What are the possibilities? Immense. Just to illustrate that, we tell the stories of a few young people with Down syndrome who pursued their aspirations no matter what difficulties they encountered. It is not what they do; it is the assurance that if they could, so shall our baby.

Our first story is about an athlete who is also an accomplished designer for jewellery, and if that were not enough he founded a rock band; he has been able to combine sports, music and a flourishing business. Our second story is about an unusual rock group – to say the least – whose leader has Down syndrome. They are possibly not representative of a "typical" group, but are very sensitive persons, highly creative and above all their leader has become their pride and source of inspiration; they do quite well, gain their living and are cited on the Internet several times. The third story is about a cheerful young lady who finds time to combine a job, with teaching, with dancing and swimming … quite an accomplishment for someone living in a large city where most cannot do that, an example of what may be called a balanced style of life. Our fourth story is about a café, snack bar and grocery store which is chiefly an academic project, an example that many times there is no need of grandiose projects to accomplish self-esteem, a sense of being useful and provide a real service to the community. Our fifth story is about a young lady to whom 20 or 21 chromosomes make no difference, and if the previous years have been challenging, enjoyable, rewarding, educational and fun looks forward to the years ahead. Our sixth and last story is about a young man who has found his means of expression through photography, has a rewarding job and cycles between job and home.

DYLAN'S STORY: AN ARTIST, ATHLETE AND ADVOCATE*

Dressed in a "DOWN SYNDROME ROCKS" T-shirt, Dylan sets down his drumsticks and picks up a microphone to address the

* Story and photos courtesy of the Community Inclusion Newsletter, Volume 2, Issue 6, November 2013, available at (http://blog.satraininginstitute.org/community-inclusion/) sponsored by the Washington State Developmental Disabilities Administration Roads to Community Living. We are grateful to Belinda Kindschi and Denise Keller for her permission to reproduce it.

crowd, "I am the founder of The Jackson Memory Band. Yes, I have Down syndrome, but that's not going to stop me from being a rock star!"

He returns to his seat behind the drums, and the band starts its set.

Dylan, the lead drummer in this Michael Jackson cover band, is a talented musician, as well as a record-setting power lifter, skilled artist and dynamic motivational speaker. A "Renaissance Man," his mom, Terri, calls him.

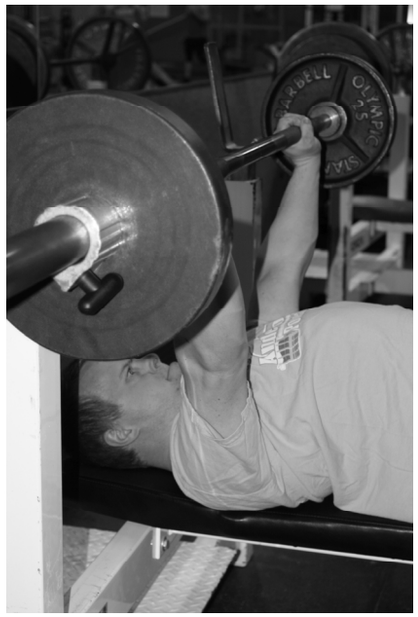
Dylan says he is a "music man" at heart. Music is his greatest passion. He likes listening to others' music and making his own.

"I've been drumming since I was 10. It came to me so naturally," Dylan, now 30, recalls. "I always wanted to build a band. It had been a dream of mine."

That dream came true about a year ago. With help from his drum instructor, Dylan recruited fellow musicians to form The Jackson Memory Band. The band has played at events such as the 2013 Special Olympics Summer Games Opening Ceremony, and recently completed a tour of Maui, the second largest island in Hawaii.

It is the band's mission to keep Michael Jackson's "Heal the World" legacy alive, while also advocating for inclusion. As the only band member with a disability, Dylan wants to help people with disabilities be seen as valued members of the community.

"When I'm performing in the band, I feel included," Dylan says. "It's all about team effort as we leave our egos at the door and become a team."



Dylan, a resident of Olympia, Washington, in the northwest corner of the U.S.A., feels that sense of belonging whether on a stage or in the gym. Every Saturday, Dylan and the other 11 athletes that make up the Elite Iron power lifting team take over one corner of the weight room at the Valley Athletic Club in Tumwater, a nearby town. In addition, Dylan has been working out with fellow Elite Iron lifter Kegan Engelke three or four nights a week since 2010, shortly after Kegan started helping coach Dylan's Special Olympics power lifting team.

Kegan and the other Elite Iron lifters hold Dylan to high standards in the gym. Just as any of his teammates, Dylan is expected to load and unload plates, spot his teammates and lift as much weight as he can with perfect form.

"Nobody treats him as a special athlete. He's treated just like one of the guys," Kegan says.

Dylan agrees, "They may be tough on me, but that's just their way of getting me to do better."

The Elite Iron team belongs to the World Association of Benchers and Dead Lifters (WABDL). Dylan competed in his first WABDL meet in June 2011 as a Special Olympian lifter. The following year, he moved up to Disabled 2 Men and Class 1 Men (non-disability division). This June, he set a world record of 330.5 pounds in the single-lift bench press for his age and weight class in the Disabled 2 Men division.

In November, Dylan competed in the WABDL World Championship, taking home first place finishes in bench press and dead lift in the Disabled 2 division, as well as a third-place medal

in bench press and a sixth-place finish in dead lift in the Class 1 division. It is Kegan's goal for Dylan to have a serious shot at winning the Class 1 World Championship someday.

"When people see Dylan at the gym, I don't want them to say, 'That kid's strong for having a disability.' I just want them to say, 'He's a strong guy,'" Kegan says, adding that as well as becoming physically stronger, Dylan's social skills have immensely improved and his confidence level has multiplied since joining Elite Iron.

An active lifestyle became especially important for Dylan during his pre-teen years. Around age 10, he started displaying anger and aggression, a response to being physically mistreated in his childhood, Terri says. However, a turning point came when he began to channel his anger into physical activities.

"I found martial arts, a drum set, dance and art. We put those four things in his world very intentionally, essentially, to save him," Terri shares.

These activities served as therapy. A painting instructor was needed mostly to help Dylan manage his emotions, particularly his fear of being imperfect in his art. Terri describes Dylan's first paintings of a wolf and a panther as dark and sinister. He wouldn't let anyone see him paint, nor would he allow an audience while he danced or played the drums.

But in time, he learned to forgive himself for making mistakes, and the colors and tone of his paintings began to lighten. It took several years before he let others see him paint and dance, but he eventually discovered a love for creating and performing.

"Art to me doesn't act as art. I am the art; art is me," Dylan expresses. "It makes that thumping sound of my heart that makes me feel good, and it gives me joy. Art – and dancing – heals my wounded heart."

Through the years, Dylan has built a career around the things he loves to do. In 2005, he founded DK Arts, a visual and performing arts company, allowing him to utilize his creative, performance and public speaking abilities as an artist and motivational speaker.

Dylan started selling his paintings on greeting cards, calendars and more. In recent years, he has also learned to cut and design unique fused glass jewelry and decorative tiles. His

creations are sold at Ventures in Pike Place Market, an old public market in Seattle, and as far as the Pacific Northwest Shop, a boutique in Sacramento, Calif. and a few shops in downtown Olympia.

With his mom's help navigating and networking, Dylan has been hired as a motivational speaker at a variety of venues including an art gallery in Amsterdam, Holland; local, national and international disability-related conferences such as the World Down Syndrome Congress in Ireland; and many employment-related conferences. He speaks about entrepreneurship and ends his presentation with a dance or martial arts demonstration. The audience is always educated, entertained and inspired, according to Terri.

Outside of his business, Dylan also gives back to his community. Since the age of 19, he has volunteered as a stocker at the grocery co-op across the street from his apartment, which is located above his mom's garage. In that time, he has gone from 100-percent side-by-side support to 100-percent independence.

"I think it's fun to volunteer at the co-op and to meet the customers," Dylan says. "I like providing good service to the community, and it builds character."

Terri has always made it her mission to provide her son with opportunities for community inclusion and access to integrated experiences. This has been crucial to his development and his success in finding what interests him, she says.

"Dylan feels that he is part of this community, and he knows he's a role model," Terri expresses. "He is a new face and a new voice of disability. It's not about disabilities anymore; it's about abilities."

As a parent, Terri tries not to limit Dylan and encourages him to "dream big." It is one of Dylan's goals to build a second band – one that plays children's songs. He also has academic ambitions to attend college, with an interest in studying video game design or history. Currently, he is working with private tutors to study for the General Educational Development (GED) test to obtain a high school degree.

In his motivational talks, Dylan shares advice that he appears to apply in his own life, as well.

"Believe in yourself," he says. "Let nothing stand in your way of fulfilling your dreams."

MIGUEL TOMASÍN, LEADER AND DRUMMER OF LOS REYNOLS,
ONE OF THE MOST IMPROBABLE BANDS ON THE PLANET*.

It is the first floor of an old house in a Buenos Aires quarter: avenues, trees, cars, women with their shopping bags. There, in the first floor, three thin men and a fourth, short and chubby, listen to Roy Orbinson.

In that old house there are several rooms, on each one electric guitars, Jimmy Hendrix posters, desks, blackboards. A sign of *Efimus*: *Escuela de Formación Integral del Músico* (School for the Integral Formation of the Musician). Three of the four men wear beards and are alike, interchangeable. Not the fourth, he is different, and says:

—Down syndrome is a fan club.

The bearded men smile. Their leader never disappoints them. Miguel Tomasín, the man who has spoken is 38, leader and drummer of *Los Reynols*, one of the most improbable bands on our Planet. Miguel Tomasín has Down syndrome.

—We are also Down, we are Miguel Tomasín.

Here they are, the members of Reynols: Miguel Tomasín, plus Alan Courtis, plus the brothers Roberto and Patricio Conlazo. A leader and three persons that all three resemble but not as much as they would like to this amiable and Down man.

—We want to make three masks with the face of Miguel, and be all Miguel – says Roberto.

—Do you feel an artist, Miguel?

—So it seems

***

* Courtesy of Leila Guerriero. Published in Spanish with the original title: *Rock down* in Gatopardo (Colombia-México), October 2002. We are grateful for her permission for reproducing it and approving the English translation

The first time Alan Courtis had a guitar – back in his infancy – he spent a whole and maddening afternoon playing a single note. Some journalists have said that note was a Mi. He maintains what he played for hours that epiphanic afternoon was a very masculine Re.

—I liked the sound of it. There were whole days I spent playing that chord, nothing more.

Alan is now 32, and more than his perfect attendance to Robert Fripp school he cares about his five-year stay at the strict and very military *Liceo Naval*.

—I am a Navy *guardamarina*. It was a sort of illuminating masochism. That a 12-year-old boy joins the Navy is mere craziness, but for me it was an enriching experience.

Roberto Conlazo is 33. His education was like this:

—I always felt attraction for extremism. When I was a boy I locked myself in a room for three months, and was fed through a porthole. I was recording hellish sounds, distorted, at full-volume. Once a technician told me "I cannot record you anymore, you sicken me, I am sorry". I discovered that ants shout when you chop off their heads, and I recorded the sound of dead ants. I always hated that concept of guitarist playing eighty thousand notes. Then I set remote-controlled toy bears on the tuning fork, handled the toy bear and played. Or played the chords with a small fan. Nobody on Earth may do a faster solo than that.

Patricio Conlazo is 31. He almost doesn't speak, and though he is a member of *Reynols* for a while he was the last one to find it out.

—I am now committed to the band.

—And before?

—No. Not before.

By the beginning of the nineties and just about to be graduated as lost causes, Roberto and Alan met, and together with Patricio formed Efimus, where they began to teach music for everyone. That included [people with] Down syndrome and Autism. One day – it was 1993 – a new pupil rang the academy's bell. It was Tomasín, who, as a manner of introduction said,

—Hi, I am Miguel, a famous drummer.

They believed him. He was invited to step in. They played. Nothing was as sublime as that.

—No effort had to be made — remembers Alan—. We plugged in and played, and thus the band was formed, though Miguel says he created it in 1967, when he was three years old and none of us existed.

Miguel is, they say, a man of incommensurable musical talent. Able to create music out of nothing, owner of no prejudice, tied to no convention. He chooses the destiny of the band, the titles of the recordings, the names of themes and they follow blindly because they trust him, they learn from him. The only thing Miguel had nothing to do with is the name: *Reynols*, because it was chosen by a dog.

—We made one of our *chihuahuas* to step on the TV remote control – explains Roberto – and the first thing that appeared was to be the name. It was the face of Burt Reynolds. But when our first album came out in England the man in the publishing house said we might be sued by Burt Reynolds so we decided to name it Reynols, with the "d" taken out.

In his sofa of *caña* and *almohadones* Miguel smiles. He likes, sometimes, to say that Reynols do not exist.

***

It was 1995, on one of these city parks, with picnicing parents and children riding bikes, a thousand square metres to invent calmness. It was there where hundreds of families were, suddenly, exposed to the music of Reynols. The police did the dirty work (after all there was a [person with] Down syndrome) and asked them to leave: they were upsetting the peace of the place.

They always knew it was going to be like that, that their Universe would be for a few. Now they have a hundred records printed, two tours abroad, and are a cult band from Asia to the States, passing by Europe. In Argentina they are unknown. In spite of deserving praise from the critics, in Argentina not a single recording can be found and the media is curious about the lack of distribution of their music.

—That is part of our work as well —says Roberto.

Their work is known outside the Argentinean borders. The first interest was the English musical label Matching Head, which in 1996 printed the record *Bolas Tristes*. A brief outlook of their discography is: *Oreja de tipo Oreja Simbo* (1998), *Gurteltiertapes*, Switzerland; *Loh Fenser* Patagonia (1999); *Semi Roar*, Japan, a record where guitar strings were smeared with sun tan lotion and moisturising cream; *Peloto Cabras Mulusa* (1999), *White Tapes*, United States; *Sonirdo de lo Mofifero* (1999) American Tapes, United States; *10 000 Chickens Symphony* (2000) Drone Records, Germany, which is no more than the direct sound produced by ten thousand chickens from a chicken farm in the Argentinean province of Entre Ríos; *Blank Tapes* (2000) Trente Oiseaux, Germany, which consists of the recording of blank tapes of different brands, collected between 1978 and 1998.

—Miguel changed our lives —says Alan—. It may sound exaggerated, but life is different when every week one is with a special person. Miguel, beyond what others may say, poor one or what a genius, promises hope for [humanity]. He is enjoying all the time what he does. We, as a group have maintained the purity of what Miguel wishes to say. There are parents that have a special child and put him in the cupboard. What Miguel means is to show the other side.

Productivity of Reynols as a band (they may produce five or six records in a single day) is only comparable to the generosity they bestow: interviews with Rolling Stone or a small independent magazine are equally attended. They answer to tabloids or left-wing journals, they assist on TV shows for children, ecological, musical, popular science or pose for girly magazines.

—It is not our purpose to appear in frivolous magazines, but when there is a pure message it doesn't matter the media – says Roberto – It is even more important when media is massive.

Amongst other eccentricities to which it leads this generosity was the participation on the programme "health of our children" conducted by the Argentinean paediatrician Mario Socolinsky. They went to talk about Tomasín with Down syndrome and with his own band and became the resident band of the programme.

Later on the paediatrician played with the Reynols a Pink Floyd cover "Interstellar Overdrive", in a homage recording to Syd Barret edited in Holland, and whose title is Acyd Vynill.

Another bizarre experience on TV was an invitation – at the end of 2000 – to participate in a talk show. Let's be clear: conducted by Lía Salgado. They attended for example a live transmission which had the title "Living with Down syndrome". At the end of the programme Lía Salgado asked Miguel Tomasín to convey a message for the year's end. "Love, peace and work" said Miguel. "Beautiful" she said moved, "peace, bread and work for everyone". "No" pointed Miguel "just for me!".

—Miguel suffers no social limitations —says Alan—. Buddha reached his adulthood and said "I shall retire to the woods to cleanse myself of all these social learning". Miguel didn't even enter that learning. He was already on that immensity. Miguel says that God is a hidden camera. Or a mixed bird, and we asked him how is a mixed bird, and Miguel says that is the God of the God. "And how is He?" we asked Miguel; "half camouflaged and half laser" he answers. Or you asked what is in the Moon: Miguel's answer: a screw and a cassette of *chamamé*.

—In what language do you write the songs, Miguel?

—Spanish with Chilean. It's really great.

Every time Miguel gets angry — which he seldom does — he threatens to put them inside a mirror.

***

To tell the truth in Argentina there was a single record of Reynols. But it is out of stock, and even if it would be the recording does not exist. Its title, *Gordura Vegetal Hidrogenada* (Vegetal hydrogenated fatness) circa 1995, and it is a CD case but without the CD. In the United States it is a cult thing and its price goes around fifty dollars.

—It is an idea of Miguel —acknowledges Alan—. Formats are each time smaller: first the long play, then the CD, then the mini-CD. This one reduced so much that it disappeared. It is the record of the no record; the car passing by on the avenue, the street noise.

Everyone has it, even those who haven't been born. The most revolutionary of a disc that does not exist is that exists.

As it would be necessary. Robert says it is a quite ample concept.

—It is a quite ample concept. We wished to patent the idea, so we went to the National Registry to ask if we might patent nothing but they kicked us out. But if they didn't let us it was because they didn't understand. We are not defeated yet – they said – we are going to make it sometime.

They considered the possibility to present the recording at the *Obras Sanitarias* stadium (during years the traditional scenario and consecratory for national musical groups), not selling tickets, invite no one and perform a recital of nothing to present a record immaterialised.

—Why not? —Alan asked himself—. If one has a band we are supposed to produce a record a year, a tour, a record next year. Why? Everything has lost so much of its value that people when playing are not thinking about music but the number of records to be sold, and be amongst the first places on the list of popularity. Why would our band have to have records and if having them why would they need to be available? The only positive thing to be in media is that there are many paths, more sensible, and this way of life in general, and of music in particular (the international one, contracts, tours) leads to frustration. One has to invent our own way. We didn't set ourselves a marketing plan. To play with a man with Down syndrome might sound as a protest. If you ask Miguel "Miguel, and now what would you like to do?" He answers "Let's do three, four records in a day". In a day. Why not? Miguel planted in us the seed of the why not. One time they called us terrorists; we say we are rather extremists. Our idea is to plant subliminal bombs against orthodoxy.

So they performed unforgettable concerts that nobody witnessed: one with no audience on *Delta del Tigre*, in the outskirts of Buenos Aires; another for plants on the terrace of *Efimus* Academy, and a big event for dry ice. Sometimes they play with instruments made by themselves, such as the *roto chiva* – the tensor of a tennis racquet transformed into a guitar – the *bolomo mogal* – a plastic hose – and the *heavy cabra* – a sort of electric lute. But they can

also do without instruments, or make music with instruments they have never played before. Critics say that the Reynols have wished to erase the borderline between psychedelia and psychosis . Jim Haynes, from The Wire, wrote: "Their music is easier to feel than to listen. You feel it with all your body, but above all you feel it with your soul".

—Yes —acknowledges Roberto—. The Reynols have written many good things, but really we don't care, because if you ask Miguel, "*Che*, Miguel, you appeared again in The Wire" he answers "What do I care?" And then he does care indeed. To be with Miguel produces a state of grace unbelievable, and nothing else matters. But it is not either a sort of nonsensical nihilism. It is a nihilism with meaning. Miguel talks a lot on objects. You watch him and he is talking to a pencil. You say "Miguel, what are you doing?" and he answers, "nothing; things of my own" And yes, why not talking to a pencil?

Vanguard of vanguard, psychical music for the unknown side of the mind. That is what the Reynols do. But Miguel says they do music for every audience, and for every world. That the Reynols music is an empty bottle with feathers of little birds acting as a planet reductor.

—According to you, Miguel, what kind of music do you all do?

—And... romantic music.

***

It might seem a congenial experience of three deluded people had it not been that Eddie Vedder, from Pearl Jam; Beck and Thurston Moore, from Sonic Youth are fanatical of the sound of the Reynols to the extent that Moore attempted that the band played together with Pearl Jam and Sonic Youth in a concert in New York. Might seem a snob oddity had it not that in the year 2000 Reynols made a tour in the United States which included 27 cities, and it included the Lincoln Center in New York, where they were invited by the American contemporary music composer Pauline Oliveros. Had it not because in 2001 they repeated the magical mystery tour in almost 60 cities of the same country, and became the Revelation of the No- Music Festival in New York. They met Oliveros in 1994, when she was in Argentina. The Reynols participated in a concert

in her honour playing trumpet and trombone, two instruments they had never played before. She, they say, fell in love.

—After that concert —says Alan— we performed on the Internet in 1999, she in New York and we here. Then we made a remix entitled Paulina Oliveros in the Arms of Reynols.

That year of 2000 they were invited by Oliveros to participate in the concert Lunar Opera, Deep Listenin For-Tunes, at the Lincoln Center. In 2001 they toured, this time to over 60 cities in the U.S. The starting point was the No-Music Festival of New York, the most important event in experimental music, where they shared the stage with Lee Ranaldo and the Nihilist Spasm Band, amongst others.

But if the aim of Reynols is to divulge the philosophy of their leader all over the world, Miguel does not leave home. He cannot travel without a person looking after him, besides he is convinced the United States does not exist, that from Mexico upwards there is only water. So the band tours with the recorded voice of his leader and a poster – shaking – of his face outspread on stage. This is a way, as any other one, to say that even Miguel cannot be seen he is present.

***

Once a year the Reynols play live in Argentina. Amongst their favourite recitals there is the one they performed at *Escuela Número 36* where Miguel Tomasín studied. An apotheosis of more that three hours before an audience of 150 schizophrenic, psychotic, autistics and Downs cheering their leader. “To-ma-sín, To-ma-sín!”. After these kind of experiences it makes it very hard to play before “normal” audiences. Now, besides Reynols, Roberto, Alan and Patricio have a new band whose drummer is also Down: Juan Manuel Acevedo. This new band is named No Reynols, and on it Roberto is called No Roberto, Alan No Alan, and Patricio No Patricio.

—No Reynols is much more primitive than Reynols. Beyond the cave —says Roberto.

If bands use to face their projects one by one, Reynols shoots nine at the time. Now-a-days they work on a recording entitled *Roniles*

Dasa Celebro, for Japan; another in collaboration with Pauline Oliveros (*Half a Dove in New York, Half a Dove in Buenos Aires*) being edited by the Norwegian label Smalltown Supersound, from Oslo; *Air Amplification Mogal*, a work done based upon amplified air produced by SSS Records in the United States; *Live in Bloomington*, a limited edition with a magazine format; *The Bolomo Mogal F Hits*, that is going to be printed in Belgium and is possibly the closest to a recording that Reynols shall ever do; *Reynols & Prick DeCay*, to be printed in the United States; *Live in Ohio*, a simple vinyl with a live show recorded live in Ohio, printed by Blanck Bean & Placenta, from the States, and, above all, a recording with intentional and political sense: *Sounds From the Argentinean Cooking Pot Revolution*. The sound of the *Revolución Argentina de las Cacerolas* (Argentinean casserole revolution) is no other than a 50 minutes long CD with the sound of the casseroles, simple and crude thunder with which people from Buenos Aires threw out of office two presidents, between December 2001 and January 2002.

—That of the *cacerolazo* was a spontaneous project —says Roberto—. As soon as I heard a tap, ten, twenty I said “I am going to record this, for it is unbelievable”. Alan, without knowing it did the same, and Miguel went out to his balcony to tap casseroles. We three had been an active part hand have made an imaginary triangle of casseroles.

The record is still on the search of a recording label (England, Germany, The States or all of them together).

—The idea is that it has a wide distribution —says Alan— so it creates conscience outside of what happened here. CNN is like a sensationalist news, but with steady cam, and remained with the image of a boy throwing stones at the bank. For the rest of the World post-casserole Argentina is a barbarian territory, that is why we selected the title in English, we wished to be understood by the English-speaking people. There are few Americans that have the notion of one not limiting to believe “This is my country, f*** the rest” They are convinced that they are the goodies and the rest of the World the baddies.

Soon they shall edit an octuple (eightfold) box in the United States with unpublished themes. They like extremes. Huge things and

very small ones. Microscopes and telescopes. Verify that the large is repeated in the small. Sometimes, by night, they go to the terrace, set the telescope towards the galaxies and spend hours reviewing stars, observing the tranquil burst of the Moon.

—Well, now we wish to make a chant.

Afterwards they remain silent, motionless. Close their eyes. Breathe. And on that shell of silence they drop a powerful bellow, the obese chant of a stone, until Miguel closes his eyes, covers the nose and emits the sound of a light bird.

—Did you like it? —asks Roberto—. It is called harmonic chant. Harmonises the chakras. In the United States we played that for fifty minutes. Audience could not raise their hands even to clap.

Afterwards silence.

—Miguel, *¿vos también sos extremista?* (are you also an extremist?)

—No. I am Argentinean.

And again silence, as if that were also music.

NATALIA CAROLINA LÓPEZ SALDÍVAR: A WORKING GIRL WHO FINDS TIME TO TEACH, TO SWIM, TO PAINT AND TO DANCE*

"My name is Natalia, and my friends call me Nati" says a 31 years old lively woman, sitting on a chair with her legs folded in one of the corridors of *Comunidad Down*, just opposite to the garden, where we are having this conversation. Friends and teachers pass by and everybody greets her; she responds with a smile.

She joined *Comunidad Down* when she was very young, for early stimulation, and stayed there, studying first and working afterwards until the employment office got her a permanent job, almost ten years ago.

"Here I learnt to walk, to speak, to read and to write". Then she took a computing course and found she was particularly able with it, and also became a fan of swimming and dancing. Computing has proved to be very useful in her working life and to

* This was a spontaneous interview with Manuel Guerrero; with contributions of Juana Inés Luna and Marta Santana

swim and to dance are major reliefs to daily effort. She is so keen to swim that she won a special diploma.

It was precisely one day she was rushing from the dance room to the pool that we met. "I have had quite a hectic day" she said, and stopped for a second to tell me about it. How nice it must be – I thought – to be able to balance one's life in such a way; in Mexico City everybody rushes all day long with little or no time for a hobby. Nati has two, and besides finds time for other activities. Could you tell me your story for a book? I asked, and with a smile she said, "Fine, I would love to share it with others; shall we meet here the day after tomorrow?"

After completing her first levels she joined the agency for labour formation, in the same school. "I made biscuits, I made many things; I love this school because here everybody treats me as a person".

— "I am a working girl with Down syndrome" she says proudly of herself.

She lives with her parents, but they support her a lot and encourage her to make a life as independent as she wishes. She moves by herself to and from her job where she works three days a week. The other two she is teacher assistant at *Comunidad Down*, helping students in making soaps, aromatic oils and other handcrafts. Besides she also helps with the school cooperative attending customers.

Natalia is assertive and intuitive, and has great expectations to develop her full potential: she wishes to learn English, drive a car, and – why not – go to College. She is also very sociable. "I have had many boyfriends", she tells me "but do not write down their names!" she warns me. How could I?

She goes with her mother to the market and sometimes she pays the bill. Working has developed her self-esteem.

Her first job was for a pharmaceutical company where she packed products and helped in the warehouse. She remained there for two years until they moved their office away from Mexico City to the north of the country. So she found another job in an insurance company which had the additional advantage of being nearer home. She began as office assistant until one day she asked her boss for a computer, "If I have access to one I can do more things" and so it happened. Now she does data capturing. She is

happy and tells that their work mates made her a cake on her birthday. She has been with this job for seven years now.

She is a woman of her time: carries a modern cell phone with which she texts her friends and uses all social networks. Sends congratulations on her friends' and teachers' birthdays. "They were first my teachers but now they are my friends," she says happily.

"When I was a little girl I was skinny and very, very quarrelsome". "I used to hit my brother two years younger, though some times he hit me back." And what did your mother say? I asked. "To defend myself" she replied. As simple as that.

But it was not so simple at the beginning. She spent some time in hospital due to health problems; her parents, as every other parent, had to learn to live with Down syndrome. "Now it is a gift for them" she says. Her father wrote a letter she remembers moved. Tears came out when she said this. It is only emotion, nothing else.

When she had her first job she was not sure what to do, but her father was very supportive: he was happy and gave her advice. She feels beloved by her parents and brother. "They are good to me; they offer me presents".

"Please now interview my teacher and friend Marta Santana", asks Nati.

Marta knows her since she joined *Comunidad Down*; she was three and a half then. A playful and cheerful girl, somewhat shy. As she grew she was still shy but determined, she obtained what she wished. For example computing was not considered in her syllabus, but she insisted until was admitted to class, and good for her since this has been one of her main assets.

When she was twelve her interest was more in sports than girl play; she rather wore trousers and was not interested in make-up as other girls. Then she changed and now she likes to look pretty.

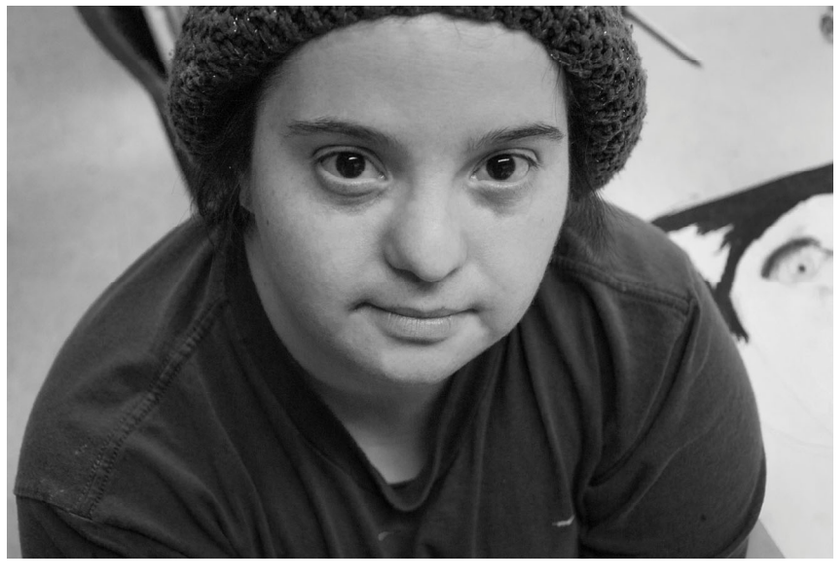
She has gradually acquired independence; from some time on she moves by her own.

"Many parents remain in their initial grief when they have a child with Down syndrome, not Nati's and that has reflected on her behaviour", are the last remarks of Marta.

Natalia paints as well, and is good at it, in the opinion of her art teacher, Juana Inés. She shows me a painting and says "she is playful, as Picasso" "She allows herself to explore techniques in painting and sculpting as well, and doesn't mind if her fingernails are ruined even if she was at the beauty parlour a few days ago."

Nati went once to see a film where the main actress posed for a portrait, and from there on she had the dream of modelling; to experiment with the emotion of the creator in front of her model. She did not rest until she convinced Juana Ines to make a portrait of her, to admire the perfection of the human body. Then she made a self-portrait.

"Nati is restless, has many projects in mind. As soon as she finishes a work she begins the next. She pays attention to herself and seeks to be alert; hardly she will be bored" is the final remark of Inés.



CAFÉ COMUNIDAD: A CONVERSATION WITH ALEJANDRA ZEPEDA*

This is a story that involves many young adults with Down syndrome, and is an example of how many concepts expressed in this book have been put to practice in a small grocery store, café

* Interview with the creators of the project

and snack bar, which sells soft drinks, basic food supplies – beans, rice, lentils – coffee, tea and biscuits prepared in the school's training bakery, as well as sandwiches and salads. It gives a service to the community and is a learning experience for the young adults that soon will leave Comunidad Down to have a job to earn their living.

What does a psychologist do working in a store? I ask puzzled to Alejandra Zepeda Rosas who heads the Project. "Everything" she answers, "this is not an ordinary café and store, it is an academic project". "Everyone has a place here; no matter how big or small are their skills". "What we care about is to develop what each one has, not what one has not".

"Direct contact with every day customers, particularly those who are not in our school, is very important since it strengthens our students' self-esteem". In this project we encourage self-confidence, independence and the development of a certainty of self-value. It allows us to work together with students in the development of social formulae, time and space notions, oral and written language, use of money, hygiene and skills to prepare meals, etc. Another very important advantage is that we avoid falling into monotony since every day customers are asking for something different (within our menu)" explains Alejandra.

Alejandra, affectionately known as "Ale" has worked at Comunidad Down since she was a university student, and there she discovered her vocation "working with persons with Down syndrome is a privilege". In those times she was a teaching assistant with young children. She left her job to finish her degree and have her baby, to whom she dedicated full time his first few years until he reached the age of joining school; then Ale applied back for her job. But to her disappoint the job was taken and the only place she could be was with young adults. At first she considered refusing the job offer until she realised that those young adults were her former pupils.

This project has been developed by Ale with two colleagues of hers, Jessica Vigil Garcés and Cecilia del Carmen Angeles Padrón, a trio with a contagious enthusiasm. "Why not try different seasonings for the salads?" – says one of them – "let's offer new products" – says the other – "so customers will be satisfied and our students will be learning new things all the time

and will not be bored". This is where the success of the project lies: forming a team among the teachers and students, where everyone knows they have an important role to play, and may develop their own creativity, a lesson that will be a key factor in their jobs outside *Comunidad Down.*

One can see the grocery store as any other in a small town: a counter, a few shelves and a radio playing music softly. A man enters and asks for a soft drink, "Martita – says Ale to a young girl behind the counter – please bring a cold drink from the warehouse". Martita brings the drink and gives it to the customer, receives the money and gives the change, under Ale's supervision. "There are some who cannot give the change that easily, then I come to their help". "There is a place for everyone here, no matter how few skills they may have: if they cannot read I place drawings of objects in their right place on the shelves, to help them with the storing". They identify the drawing and it helps them to develop their communication skills a little further.

Teachers place their orders for lunchtime. "That is easy because they know them, so they go and supply the goods". "They understand perfectly well the instructions, all I have to do is to speak clearly and make sure they have understood; hardly I have to repeat an instruction". Passers-by ask for a soft drink or water; "we have snacks and salads today" the attendant offers. This is educational both ways: to customers because they appreciate how persons with Ds have skills enabling them to develop naturally in a society, to them because they lose their apprehension to do so. This will give them a better platform for a permanent job in the outside world.

"In the little time we have been operating – just above three months – youngsters have made a leap forwards. How could it not be? They are happy, treated as persons, as Natalia said in her interview, and developing their independence. "This is a proof we are on the right direction" says Ale.

Ale studies carefully each of her new students, she "scans" them, and centres her attention on their main skills which are developed according to a rigorous academic programme, since as she said at the beginning this is what the project is all about.

There were obstacles she had to surmount at the beginning, including scepticism from some, but they pledged to the idea …

and succeeded, partly due to the enthusiastic support of Norma García, the Headmistress of *Comunidad Down*. They began selling doughnuts from room to room. Their price was 9 pesos, which was intended to force the salesperson to give change, since the closest coins are 5 and 10 pesos. Some asked for help, but pulled their weight. This way they developed the confidence some lack, increased the inventory and services. Eventually they were assigned a small room, at the entrance, so they could serve both personnel and passers-by. "I had only to awaken them", says modestly Ale.

"Our young adults can do much more than some believe", she says proudly of her students. "As any person, the more information they manage, the better they will develop in life". And that may be the summary of the mission of "*Café Comunidad*": to strengthen their agility in their minds, since they will not be forever at school.

"It is not a matter of adapting the world to them, but rather to adapt them to the world they will live in" says Ale smiling.

JASPREET KAUR SEKHON, AN INDEFATIGABLE LADY OF HER TIME*

When I first met Jaspreet, a few years ago, I found her to be a fashionable young adult who would beat out the competition in a Bollywood dance off. I couldn't help but say hello.

Jaspreet was diagnosed at birth with Down syndrome. She explained clearly that she was about 10 when her parents told her about Down syndrome and how she was born with 21 chromosomes. To her, it didn't make much of a difference. Feeling a little surprised, it was then that I learnt about Down syndrome being a naturally occurring chromosomal arrangement that has always been a part of the human condition. Facts like it being universally present across racial, gender or socioeconomic lines, and affecting approximately 1 in 800 live births, intrigued me. Although there is considerable variation worldwide, Down syndrome usually causes varying degrees of intellectual and physical disability and associated medical issues.

* The content/excepts have been extracted from Cheryl Baines's article in the June 2014 issue of India Se magazine (www.indiasemedia.com), the leading magazine for the Indian Diaspora in Singapore and South east Asia. We are grateful for her contribution

My friend, Ms. Jaspreet Kaur Sekhon is now a fashionably dressed lady of 33 years, and has been diligently working as a Teacher's Aide for 13 years. An active member and self-advocate of Down Syndrome Association Singapore, and an Ambassador of Down Syndrome International; she is a sprightly young lady who adores music and dance; traveling and meeting people.

Her father, Dr. Balbir Singh, is a 3rd generation Singaporean. Jaspreet's parents hail from the pioneering generation of Sikh families that emigrated from India. Jaspreet has a gorgeous younger sister, Parveen, an adorable brother-in-law, Florian and a very cute nephew, Max.

Her mother, Rabinder Kaur, taking a keen interest in helping her start reading at an early age is what comes to Jaspreet's mind as she reminisces about her childhood. "My special education school was boring; I did not enjoy [much of it]. We [did] not have much of a choice for our education to be more challenging. We are slow learners but we can catch up to some extent, if given the chance", she said. Jaspreet shared with pride her participation in some interesting programs outside of school.

A friendly child at the age of two, Jaspreet participated in a home-based Early Intervention Pilot Project. Always eager to see her therapists and diligently completing homework assignments; she did so with her motivation mantra "I can do it!"

The next 12 years, saw her schooled in the special school system for the Intellectually Disabled. After joining the system, Jaspreet felt the desire to interact and learn more from co-curricular activities. Her supportive parents helped her join mainstream playgroups, kindergarten and speech and drama classes. Through these programs she was able to provide the challenge she was desirous of for herself and explore in her learning.

Meanwhile at school, aside from regular subjects, Jaspreet included Badminton, Swimming and Home Craft in her day-to-day curriculum. Self motivation coupled with supportive teachers brought confidence and joy into learning. Reflecting on her education, she says "The last 13 years have been challenging, enjoyable, rewarding, educational and fun. I look forward to the years ahead."

Like all school kids, there were days Jaspreet didn't feel like going to school. To my utter shock, she recalled the few times she was reprimanded rudely for reasons that did not make any sense to her. But, with a little endurance and sheer determination, Jaspreet went on to become a Prefect and School Ambassador. She proudly credits her achievements to teachers and principals who stood by her. She smiles warmly and acknowledges them as her sole inspiration in her becoming a Teacher's Aide.

Jaspreet, along with her father, strongly reiterate the fact that people with disabilities are also gifted with abilities and talents. When visiting doctors, Jaspreet faced difficulties in dealing with doctors who weren't as aware and open as perhaps her father is. Speaking from experience in her Appeal to Health Providers speech Jaspreet states, "I have heard how negative doctors can be, especially when breaking news to parents who have just had a baby with a disability." In this speech she continues, appealing to doctors dealing with parents to encourage parents accept and recognize their child's many abilities. Like me, Jaspreet believes in sensitizing and making people more accepting of their family members affected by Down syndrome.

A sizable and tangible change can be contributed by educating doctors about their attitudes and approach to patients with disabilities. According to Jaspreet, some doctors in the past have focused solely on physical health as opposed to emotional

health; not realizing the impact of their approach on Jaspreet and her family. "We need your advice and support. Make us feel comfortable and not afraid", Jaspreet appeals. In the same speech she also goes on to call for more easily available medical care and consistent treatment with follow up checkups. Jaspreet ends her speech with "believe me, we too can have a good quality of life and a healthy one too! With your help, we can manage our disability better and keep contributing to society."

Things that matter often come with botheration. With her increased knowledge and awareness about Down syndrome, she finds it highly inappropriate for teenagers and adults affected by Down syndrome to be referred to as children. Pondering over the issue has increased her stance in this regard, often making her correct people who use the word 'child' in reference to someone with Down syndrome. Jaspreet sincerely urges everyone to empathize and award due respect. In one of her many speeches, Jaspreet has addressed this form of labeling with "We grow up like everyone else. We too become adults. So do not call a 30-year old a 'kid' just because she has a learning disability. Your language and how you treat us must be age appropriate." Having said this, she is brave enough to command the respect she deserves as a human being.

With many notable achievements to her credit, the year 2014 saw Jaspreet being invited speak at the Panel discussions on "Health and wellbeing – Access and equality for all" (on the occasion of World Down Syndrome Day) at the United Nations, in New York[†]. In her speech, she shared some of her thoughts on the attitudes of healthcare professionals and appealed for their professional care and voiced her appreciation for the excellent work that they did. She also addressed the important topic of how people with Down syndrome could possibly contribute to their healthcare. "I felt very privileged to be invited by Down Syndrome

[†] See http://www.worlddownsyndromeday.org/jaspreet-kaur-sekhon, http://webtv.un.org/search/health-and-wellbeing-%E2%80%93-access-and-equality-for-all-on-the-occasion-of-world-down-syndrome-day-panel-discussions/3389909365001?term=down%20syndrome#full-text (see particularly the 24:30 minute mark; available in English, Portuguese and Spanish), http://www.worlddownsyndromeday.org/sites/default/files/Keynote%20Jaspreet%20UN%20presentation%20-%20powerpoint.pdf (only in English), and http://www.worlddownsyndromeday.org/wdsd-conference

International to speak about health and well being from the point of view of a person with Down syndrome." She awaited the day with great hope and couldn't believe when the day arrived! Maintaining her composure amid experts and ambassadors, she spoke impressively. It was a great moment for her and for Dr. Balbir.

Dr. Balbir shared his experience too, "Having been one of the pioneering advocates to have embarked on Inaugurating World Down Syndrome Day on 21 March 2006 in Singapore, and then seeing WDsD recognized by the United Nations as an Official Commemorative Day in 2012, it was a proud moment to be addressing the WDsD Conference at the United Nations on 21 March 2014 along with Jaspreet."

After graduating school at 19 years old, Jaspreet secured her position at the Maris Stella Kindergarten as a Teacher's Aide. Successfully completing the Certificate Course for the Association for Early Childhood Educators (AECES) made her professionally qualified and equipped for her career.

1998 saw Jaspreet being elected Ambassador for the Association for People with Special Needs. Nominated by the Down Syndrome Association, she conducted an informative talk for the students of the Gifted Program at the Raffles Institution.

1999 was the year that branded her a true ambassador of Down Syndrome Association. Jaspreet presented her paper titled My Oz Travels at the 7th World Down Syndrome Congress in Sydney, Australia. Chosen by the committee to open the 8th World Down Syndrome Congress in Singapore, Jaspreet made a welcome speech for delegates from 35 different countries and the President of Singapore.

The noble journey continued with Jaspreet speaking at a meeting for the Toastmasters Club of Singapore in September of 2001. She, in addition to speaking at various esteemed meetings, has her own dedicated CD for the National Institution of Education. Interestingly the talk opens with "Hi, I am Jaspreet. I would like to share with you some tips when working with children with Down syndrome". She has contributed responsibly in raising awareness about Down syndrome through her interviews to the media.

Jaspreet is such an inspiration and her story is incomplete without a befitting mention about her creative pursuit in

Bollywood Style dancing (a dance form originating from hindi films). As someone who dances with passion and grace, she was invited to perform with the professional dance group Apsara Dancers. Besides performing solo for an open house at her school and Down Syndrome Association's awareness week, she has also performed at the Down Syndrome Conference in Jerusalem, Israel in 1999. Jaspreet was also part of the Down Syndrome Association's creative dance group that performed in Osaka, Japan and Sydney Australia.

Loving walking the ramp/catwalk, Jaspreet has modeled clothes for the esteemed newspaper of Singapore 'The Straights Times' and jewelry created by the Physically Disabled for a fashion show.

Over the years, I have witnessed Jaspreet attaining more fitness and a slim silhouette, fitting into beautiful apparels and looking fabulous with ease. She took swimming seriously and represented the Down Syndrome Association at the National Swimming Championship for the Disabled. Not only did she participate, she went on to win 5 gold medals in the September of 2001.

Over my afternoon meeting recently with Dr Balbir, an endearing dad, at the Singapore Cricket Club, Dr. Balbir spoke with a selfless love and passion about the Down Syndrome Association, his wife Rabinder, younger daughter Parveen and their real day to day challenges faced in raising their 'baby' a special needs child. His tremendous knowledge and moving conviction surpasses a layman's thoughts of being 'sensitive enough.'

Dr Balbir stated in slow enunciation, "Certainly it was a difficult situation for us, especially when you are not prepared for it. The whole scenario looked even more bleak, as there was not much information forthcoming; whatever we were told was negative. There was much stigma having a child with a disability."

Situations always crop up in life. Strength to accept and cope with the situation always rests in love, family and knowledge. Rooting on their strengths, they pulled themselves together, did some soul searching and discussed it with their family members. Balbir's family did not disappoint them; showering them with their unconditional support and love. To help themselves and their

loving daughter, Dr. Balbir and Rabinder attended overseas conferences. On such trips they were successful in tapping into valuable resources. This not only enabled their learning about Down syndrome but also induced innovation and positive motivation in coping and overcoming numerous challenges, especially at every transitional stage of Jaspreet's life.

Jaspreet smiles and maintains that it takes a long time and lots of effort to change people's attitude. "Yes, I have had problems in society and at work sometimes but I'm glad things are slowly changing. We do get bullied, labelled and stereotyped but when I can, I try to question people" she said.

Reflecting upon her life so far, Jaspreet says, "The last 13 years have been challenging, enjoyable, rewarding, educational and fun. I look forward to the years ahead."

Like all good teachers, she is constantly engaged in working towards bettering her skills in fulfilling her responsibilities as Teacher's Aide. Her truest joy is to see her students do well. Today Jaspreet leads a fairly typical life. Her love for children inspired her to pursue this career. She says "I think I am quite patient and caring with kids. As in all jobs - there are ups and downs and I try to deal with it. At the end of the day, I enjoy my job".

Jaspreet is also looking forward to being an active aunty, a new role, to her adorable infant nephew, Max who has now moved to live in Singapore! Speaking of future plans, Jaspreet reiterates in a soft tone, "I am like any other person. I will keep on trying to make a difference in our lives by speaking up, so that others can understand our feelings and dreams; Yes we have these too!".

The world will always be in need of humanitarians like Dr. Balbir and it's no surprise to learn of his future plans. Having chaired the WDsC 2004 Conference in Singapore, He has been appointed Advisor to the World Down Syndrome Congress 2015 to be held in August 2015, in Chennai India.

A recipient of the President's Special Recognition Award (2011); the PBM Medal (Pingkat Bakti Masyarakat) in recognition of his commendable service in the disability field and social service sector by the President of Singapore; Dr Balbir Singh has been an active advocate for the intellectually challenged (Down syndrome in particular) for more than 25 years.

Having served in numerous voluntary organizations and government feedback committees; and being a Past President and existing Board member of Down Syndrome International (DsI), Advisor and Founding Chairman of Down Syndrome Association Singapore, he has served as a Board member of the National Council for Social Service, Singapore.

Jaspreet and Dr. Balbir are an inspiration to many and they make a profound impact on everyone who meets them.

"To my friends, do not give up. The start is always hard. We have our goals and dreams. With the right support and guidance, we can achieve a lot. Be determined, work hard and you will not be disappointed." - Jaspreet Kaur Sekhon.

"I owe all these to persons with Down syndrome in Singapore and globally, my family, many supporters, friends and fellow Board members and the Almighty for giving us the strength courage and wisdom not only to manage and cope with having a child with special needs, but to move beyond this situation " - Dr. Balbir Singh.

ENHANCING THE COMMUNICATION OF A MAN WITH DOWN SYNDROME BY MEANS OF MODERN TECHNICAL COMMODITIES*

David de Graaf, a Dutch male with Down syndrome, aged 31, is

involved in very many activities. Firstly, since the change of the century he holds a part-time job at the national office of the Dutch Down Syndrome Foundation (SDs) in Meppel, The Netherlands‡, for which he is paid. He does all kinds of work on the computer coached by his colleagues up to simple graphical lay-out work. He voluntarily serves as a waiter, notably on Wednesdays, Saturdays and Sundays, in a tearoom

* Written for this book by Erik de Graaf, senior consultant at the Dutch Down Syndrome Foundation. We are grateful for his contribution

‡ This is about 100 km northeast of Amsterdam, in the beautiful Dutch countryside.

in a beautiful surrounding in a nature reserve at Sint Jansklooster. David lives as a roomer in his parent's house in a small country village. From the house, his job in Meppel is 7 miles due East and the tearoom in Sint Jansklooster 7 miles due West. So, the house is situated in the middle of David's main jobs. Because of the extremely limited public transportation, David has to travel on his own by bicycle. As such, over the years, he has logged more than 30 thousand miles!

During the week he makes his own meals, washing-up and laundry and has his own TV and PC. Only when things get too difficult for David his mother Marian and his father Erik help him out.

Since David is no fluent speaker, to learn more about his experiences during a day outside his home and family his parents gave him a simple digital camera way back in 2001. Not photographs as such were their goal, but the inherent communication aspect. Right away David used it intensively. 'For my report', as he used to say. And this suited its purpose very well besides following a family tradition!.

In the course of time David got better and more versatile camera. Of particular importance was the moment in 2003 when a picture by him was used during a weather forecast on Dutch TV. From then on David would –with his father's support- send in pictures regularly that were used every now and then, too.

During the years David produced more and more photographs that were really worth showing, i.e. as a picture rather than for their report value (you may see some of his outstanding photographs at www.daviddefotograaf.nl - text in Dutch). In that sense, since September 2010 David continuously produces photographs for –again- the weather forecast in his local newspaper appearing thrice weekly. Furthermore, he also uses his photographic abilities for his job at the SDs and for his other activities.

To enable David to give a presentation for his class during his school years, despite his speech problem, his parents and he started to produce real tailor-made presentations, to be read aloud in front of his audiences, with programmes like –nowadays- PowerPoint. His parents take care of the actual text and the technicalities, trying to (re)formulate things David has said earlier in relation to the

main topic at hand or in answer to questions posed to him. Another source is preparing, as good as possible, what they think David would like to state from his point of view about that particular subject. Subsequently, the three of us start to edit over several days in a row, adding what should be added, cutting out what is obsolete, changing photo's to more recent or better ones, replacing words that prove too difficult for David to pronounce. Therefore, in fact, David's situation is more or less comparable to that of a

CEO with a handy secretary. (David also feels like that!) This procedure has worked and still works very well too! In the meantime, David has presented regularly about his hobby's and his work, but also about his personal experiences with early intervention seamlessly transferring into continuous intervention, illustrated by many video-clips of he himself as a baby, toddler, teen and grown-up. This is informative and helpful for an audience of new parents of a child with Down syndrome. And David loves to present (http://vimeo.com/86432725*). To keep things real, in every presentation screens there is a statement added like: 'I did not make all these photographs and video clips all by myself. For most I was way too young then. But I did experience it all as you have seen. And I did not write the accompanying texts. But yes, VIP's always have others write for them! And yet they know what they are talking about. And so do I!" .

Since January 2013 there have been several exhibitions of David's best photographs, drawing quite some public and media attention. Presently, the tenth one, in the local hospital, is in preparation.

* You do not need to understand Dutch to see how much David enjoys talking and captivates his audience

Nowadays, David is well-known regionally for his photography, a fact that strongly supports his social network.

The illustrations show David, mouse in his hand, at the official opening presentation at the start of a recent exhibition as well as a ‘selfie’ with his present camera.

Those are not the only activities David enjoys. He loves circus performances as well. As such he also is a voluntarily crew member of the ‘Okidoki’ children’s circus in the city of Meppel under the guidance of Marie Tiggelman. Photographic documentation is part of the job.

Remaining in perfect shape, even more so than simply by his cycling, David spends many early morning hours at Fitland fitness, likewise in Meppel. Another important hobby is ballroom dancing. Together with a gifted dancing teacher assistant they won several national championships in the related type of competition.

The birth of a baby with Ds brings changes in many ways to thelife of a family, but if the necessary skills are developed among parents and child a good quality of life can be achieved. David’s story exemplifies how family working together with an individual with Down syndrome can help a person attain maximum abilities which can result in a more happy life.

12

A PHOTOGRAPHIC ESSAY

Raúl Campero

Few experiences can give such a wide perspective that deeply affects life, to a shift in paradigm that has been maintained before.

I must confess that when I was invited to participate in this project, I had mixed feelings that, at first, I found it difficult to overcome. Mostly I felt afraid. I imagined that the Centre that I would have to visit daily for some time would be something very similar to an institution for the mentally ill and that I would have to be very careful not to be the target of aggression or to get into complicated situations. Little did I know that what I was going to find there was quite the opposite.

The people I met there taught me a lot about disability, but better still about ability. People who live life fully, people with paid jobs, with worries, with hobbies, with chronic diseases and full of vitality. People with likes and dislikes, with joys and sorrows, with intrigues and curiosities. Children playful and mischievous, young people concerned about fashion, adult sportsmen and others not so much. Artists capable of making you feel deep and complex things; fnny dancers and enthusiasts. People who made me think that maybe it's me who has a life full of limitations and not them.

From the very beginning I was received with great affection and from that point onwards only a friendship grew. They made me part of their community without much more than sharing a smile and allowed me to enter their lives with a camera, to try to record and relate something of what I lived with them.

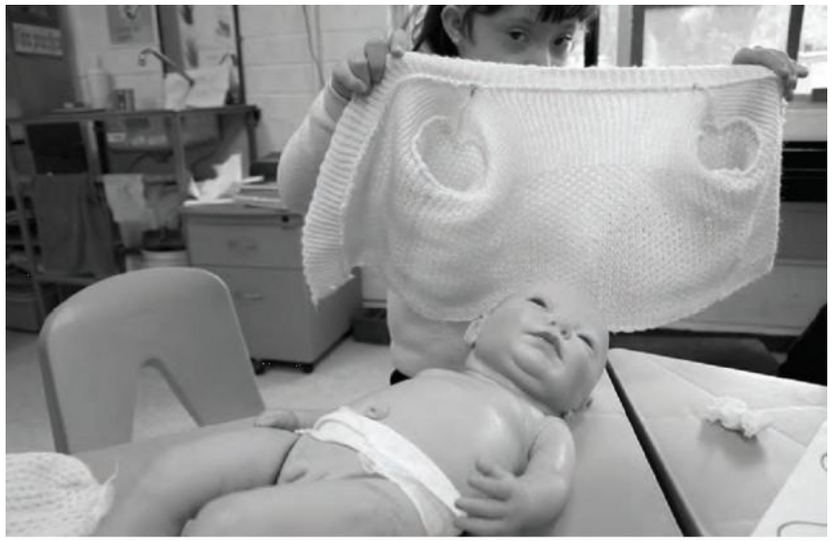
Mauricio
When I arrived on the first day, I was introduced to Mauricio as one of the most sociable and talkative members of the bakery. The first thing he told me was that a few days before he had met a famous singer of Mexican vernacular music, which he was very proud of.
That was the only contact we had during the first days. Apparently, my presence made him remain silent. A short time later, while I was looking for an angle trying to photograph Maria Felix (one of his companions), Mau passed me with a tray of cookies ready to put it in the oven and just before doing it turned to show me. He stopped for a moment to pose for a couple of photos, all in silence; then he thanked me with a big smile and continued his task as if nothing.

Autism and Down syndrome
.

There are cases in which Down syndrome and autism are combined, although usually they are not diagnosed together. Héctor has both and that means he has a limited verbal communication, but also that he is better than his colleagues in more complex processes.
Many times the presence of the camera causes Hector to stare at the lens. It makes me feel that there is some degree of non-verbal communication between us.

End of day is approaching
The school kitchen of is attended by students with the support of teachers. Its function is to provide healthy food to students, teachers and anyone who requests a meal to be delivered at lunchtime. Once orders are collected, a more relaxed atmosphere is felt. As with any group of young people, they need no more pretexts to joke with each other. Adriana plays with her ex-boyfriend and now good friend Martin, while Ady uses the moment to pose for the camera.

Doll
With a worried face, the doll seems to know that after being selected among the many didactic materials that are in the room, a full afternoon of trying on different clothes and traveling head hung on one foot all over the place awaits. Of course, it will receive a lot of love in the process. Materials like this doll help students to understand things like the function of the different components of a wardrobe and the basic anatomy of a human being.



Self-portrait
To make the students of the art class aware of their body, Ines, the teacher, makes them draw a self-portrait helped by a mirror.

The smile
It continues to amaze me how similar the expression of the drawing and Lola's smile is, although anatomically it is not very precise. That's why it's so important that exercises like this are done by people with Down syndrome. In this way they understand better their body and the functions that each of their parts have and with it they have a better knowledge of themselves.

Natalia
Nati, as his friends call her, is one of the most adapted and developed young people with Down syndrome in school. Thanks to the constant efforts of her parents and teachers, she has been able to have a fuller life even than many of us. She works out, attends her art class, collaborates in the school, has many friends and maintains a job that allows her to meet some of her expenses and invite her parents from time to time to eat at a restaurant and pay with her credit card. She takes graphic art very seriously and develops it with the ease of a veteran painter, decides on the combination of colors and responds with firm opinions to the suggestions made by Inés about the direction of her work.

Collective
The two Adrianas, Martha and Ivan play, while putting the finishing touches to their joint collaboration. The great affective capacity that they have and that is not exclusive to this group is notorious. In general, it seems to me that most people with Down syndrome are very affectionate and have no prejudice in showing it by hugging me just because they like me.

Hands
A characteristic of people with Down syndrome is the great flexibility of their extremities and the short and rounded shape of their fingers. Adriana prepares some details of her work almost finished and press hard for the glue to grip.

Tango
Everyone participates in the choreography. I'm even surprised at how happy Hector is when it comes to dancing. They look like a couple of tango dancers. I had never seen him smile so much.

Reality aside
I can not help wondering what it is that calls so much attention in the opposite direction to what everyone else is seeing on stage. It represents the reality of many children who, like him, have no ability to communicate, and learn to live in a reality isolated from the rest of the people.

Misstep
All dance with much grace and energy for the Christmas festival. At a certain point, Karen loses her step and deviates, something that far from worrying her causes a great laugh.

Adriana's dog
In her apartment, Adriana plays with her beloved *xoloitzcuintle* dog that patiently lets her hug it. From behind, his mother looks at them affectionately. The support and involvement of parents in the development of the person with Down syndrome is of vital importance.
After meeting Adriana's parents, I can certify that the beneficial effects of this equation make an abysmal difference.

Goal keeper
Sport is fundamental in the development of any person, but because of its genetic condition and the health problems associated with it, sports take on an even greater importance in people with Down syndrome. Unfortunately, most people dislike the idea of exercising; I guess that's part of the human condition and not specific to the syndrome. What is certain is that their low muscle tone and heart disease make it more difficult for them to perform physical activity. Martha waits a long time for a goal to fall or for the ball to get close, because except Charlie and Javier, the most physically active, no one runs after the ball; they all wait for the ball to pass by them to try to kick it.

From the bottom
I look to the shore and when Jesus reaches to see me, from the bottom of the pool, he decides to dedicate me a huge smile as he frequently does.

Spa
It's time to leave the pool to go to their respective occupations. The image reminds me of a pictorial scene of American art from the 1940s.

Moustache
After one of the choreography rehearsals for the Christmas festival, Leslie, with whom I had not been able to make contact until then, comes up to me with mischievous moustache to tease me that it is like mine.

We pose with our moustaches
I decide to prepare my camera and give it to the dance teacher so that we can take a picture of Leslie and me showing off our flourishing moustaches.
As I said at the beginning, when I took this project I was afraid to do it. I met an educational community for people with Down syndrome and little by little I was not only dissipating my fears, but I have seen how we were emotionally approaching them me and I to them, to the degree of mimicry. Now, I can not feel anything other than love for all of them.

A FINAL WORD

Persons with Down syndrome have to struggle against inherent and external obstacles. No doubt the extra genetic material has consequences, but the struggle is not at odds with happiness; moreover, it can foster it. Diego has inspired this book. Around him, and the many other diegos and their families we have joined to work together and suggest specific actions along quality of life of individuals and their families; along policy making; education; health care; research in many branches. To be aware in order to understand and appreciate what we have in hand.

Life is worth living with a good quality and to achieve it is necessary to care for needs of mind, self-esteem, friendship, love and the capacity – and obligation – to contribute to society.

Quality of life axis or domains are a reference that has been explored in the past pages; not as good intentions to self help, but based upon sound scientific basis. Furthermore they have been related to recommendations of the Convention and thus constitute powerful elements for the implementation of public policy.

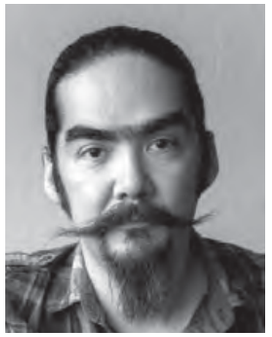
New information on Down syndrome arises every day, which is fortunate because it brings along a better life expectancy. Our attitudes and effectiveness depend much on a better understanding. There are many areas of opportunity for a better development, promoting a more open society with fewer prejudices where everyone is treated with respect. This is more at hand than many people think. We are all part of the human race and thus we all share the same rights and duties, and society must respond by providing the conditions so that everyone in a fair and equitable manner can develop, participate and have access to the benefits enjoyed by individuals regardless of their physical, economic, ethnic or other conditions. The perspective of evolution justifies diversity and diversity the richness of complementing each other.

Certainly present is much more promising than John Langdon Down ever dreamed.

Roy I. Brown

Roy has a background in chemistry, biology and psychology. His long career has spanned practice, research and teaching in the field of disabilities. He has run support programs for people with intellectual disabilities in the United Kingdom, Canada and Australia,, including programs for children and adults with special challenges in their learning and behaviour. He was Founding Director of the Academy of the International Association for the Scientific Study for Intellectual and Developmental Disabilities (IASSIDD), and also founded the Special Interest Research Group on Down Syndrome..He is Professor Emeritus at the Universities of Calgary, Canada, and Flinders, Australia. He has more than 200 published books, chapters and articles and has directed numerous workshops and seminars around the world. He has received awards from Down syndrome societies in Canada and Australia. He has been awarded the Order of the University of Calgary and an honorary doctorate from the University of Ghent, Belgium, for his contributions to the field of disabilities. Recently he receieved The Robert E. Cooke Lifetime Achievement Award from The American Academy of Developmental Medicine & Dentistry.

Raúl Campero



Raúl is an engineer in electronics from the Monterrey Technological Institute, director of photography and musician. His passion for music has made him explore several instruments, some of them little known, like the stick. As Diego's uncle he had the interest to participate in this book, not as an illustrator, but with a documentary proposal that explores through images what Down syndrome is in the context of Mexican society. He has been director of several national and international television projects and director of photography of projects that

range from cultural to advertising. He is considering making several documentary projects as an extension of this work.

Garé Fabila

Garé is the mother of Eduardo, a young man with multiple disabilities. She has a PhD in Biology from the National Autonomous University of Mexico and several graduate diplomas in Multiple Disability from the Organization of American States. She has been a member of the Panel of Experts on Disability of the United Nations, of the working group to elaborate the Convention on the Rights of Persons with Disabilities and of the working group of the International Year of the Family of the UN. She has been vice-president of the Mexican Confederation of Organizations in Favor of Persons with Intellectual Disabilities, founding member of Very Special Arts Mexico, founder of *Comunidad Crecer*, a rehabilitation centre for people with multiple disabilities, and founder of the Latin American Network of Non-Governmental Organizations of Persons with Disabilities and their Families.

Rhonda Faragher

Rhonda is Deputy Director of the School of Education and Director of the Down Syndrome Programme at the University of Queensland, Australia. She has been head of the Department of Education at the Catholic University of Australia and an adjunct professor at Simon Fraser University in Canada. She was coordinator of the Leading Aligned Numeracy Development (LAND) project for mathematics teaching and spearheaded implementation strategies to improve this education in low-income Australian schools. She chairs the Down Syndome Special Interest Research Group of the International Association of Scientific Studies for Intellectual and Developmental Disabilities (IASSIDD) and is vice president of the same on quality of life. She is a member of the Board of Down Syndrome International and an

independent member of the subsidiary of Australia. Among the distinctions he has received are the Vice Chancellor's Medal of Excellence and the Australasian Mathematics Research Group Award for his math education program for infants. She also received the Alderson award for his services to people with Down syndrome and the Commonwealth of Australia award for his services in Singapore. He has published numerous articles and books, two of the most recent are: *Educating learners with Down syndrome: Research, theory and practice with children and adolescents* and *Quality of life and intellectual disability: Knowledge application to other social and educational challenges*. Rhonda is the mother of Ruth, a young woman with Down syndrome.

Manuel I. Guerrero

Manuel is a physicist from the National Autonomous University of Mexico (UNAM), Doctor in Physical Chemistry from the Imperial College London and has a Diploma of Membership of the Imperial College in Chemical Engineering. His professional life was spent in science and engineering in research institutes and in industry. He always had a great interest in the dissemination of science from a very young age in the magazine Naturaleza of the UNAM and later as the author of two books on water, published by the Fondo de Cultura Económica. The birth of Diego, his first grandchild, with Down syndrome, gave a complete turn to his life and since then he has dedicated his effort and knowledge to this topic. With the support of distinguished specialists in the field of disabilities, he has undertaken the task of bringing current scientific knowledge to people with disabilities and their families, especially in Mexico and in developing countries. In this field he has found a new and enriching sense for his life and has appreciated the generosity of those who work in that field: proof of this is this book. His time is devoted to researching and developing projects on disability, when his duties as a grandfather permit. He currently organizes a programme on Art and Disability for the MACAY Cultural Foundation, Mérida, Yucatán.

Margaret Kyrkou

Margaret has extensive experience in issues related to health and well-being. She helps families to understand their children's medical and health needs, including aspects such as diet, sleep, hygiene and behaviour; helps finding the right doctors for their children and explains what questions they should ask. She also helps them to navigate the complex world of medical practice. As a doctor she worked in general medicine until her eldest daughter developed severe epilepsy, so she turned her attention to specialised medicine to work with people with disabilities, particularly those within the autistic spectrum. Her own daughter later presented an intellectual disability, so that her clinical experience was linked to the family, and therefore her focus is on the family and not just on the individual. She has received recognised medical qualifications after her bachelor's degree in medicine and surgery and her master's and doctoral degrees from Flinders University in disability studies. She is a Member of the Royal Australian College of General Practitioners and has a diploma in Child Community Health. She has been awarded the Order of Australia medal for services to children with disabilities.

Robert L. Schalock

Bob is Professor Emeritus of Hasting College and Associate Professor of the Universities of Kansas, Salamanca, Chongquing Normal (China) and Ghent. He belongs to several professional associations, such as the Nebraska Psychological Association, the Academy on Mental Retardation and the American Association on Mental Retardation. He is a member of several editorial boards, including the American Journal on Intellectual and Developmental Disabilities; Policy & Practice in Intellectual Disabilities; Evaluation and Program Planning; Intellectual and Developmental Disabilities; Journal of Intellectual Disability Research, and

Journal of Vocational Rehabilitation. He has published numerous books and articles on disabilities and quality of life in services for adults with disabilities; evaluation of programs; economy, industry and disability; prospects of quality of life; evaluation based on results; integral employment; intercultural perspectives on the quality of life, and diagnosis of supports for people with disabilities. Some of these books have been published with Miguel Ángel Verdugo.

Miguel Ángel Verdugo

Miguel is Professor of Disability Psychology at the University of Salamanca, director of the University Institute for Integration in the Community and of the master's degree in Integration of People with Disabilities and Quality of Life. He also directs the Disability Information Service of the Ministry of Health, Social Services and Equality. He has published more than 500 scientific articles or book chapters, and more than 70 books and evaluation scales. He has conducted research on quality of life, intellectual disability, employment, social skills and others, and has frequently participated as a visiting professor at universities in different countries, and presented papers and scientific communications. He directs the scientific journal *Siglo Cero*. Among the awards he has received are the Medal of Education of the Universidad Anáhuac 2014, in Mexico; the Queen Sofia Award 2013 for Rehabilitation and Integration, of the Royal Board on Disability; the Solidarity Award Once, Castilla y León 2013; the 2013 Intras Award; the Infanta Cristina 2010 Research Prize; the 2005 International Award of the AAIDD; the 2001 Mecenas Award from the University of Salamanca, and the honorary doctorate in 2012 by the ISALUD University of the Argentine Republic.

Karen Watchman

Karen is Professor at the University of Stirling, Scotland, and director of the online programme of the Master's Degree in Global Issues in Gerontology and Ageing. She has worked on intellectual disability, ageing and care for dementia both in practice and in academia. She acted, 10 years before completing her doctoral work, as executive director of Down Syndrome Scotland, a national non-profit organisation run by parents who study the experiences of people with Down syndrome and dementia. A central part of her work has been to make research always accessible, so that in addition to her teaching and research work she frequently teaches lectures on intellectual disability, ageing and dementia in the United Kingdom and in other countries.

ACKNOWLEDGEMENTS

Many people have generously participated with suggestions, critical reviews and permission to reproduce previously published material; they come from many countries, demonstrating that Down syndrome is a subject that makes language, geography or any other barrier marginal.

We thank those who not only wrote a foreword for the book but also made a meticulous review and enriched it with their comments: Phil Davidson (United States), Balbir Singh (Singapore) and Fernando del Río (Mexico); Phil was also kind enough to comment extensively on the genetics chapter and clarify more than one issue.

The book is about Down syndrome, so the stories of people with this syndrome who have been successful in very different parts of the world are key to our story: Juan Camilo Sierra (Colombia) invited Leila Guerriero (Argentina) who gave us a gift with the history of the Reynols; Belinda Kindschi, Denise Keller and Terri Rose gave us the story of Dylan Kuehl (United States); Natalia López (Mexico) told us her own story and Alejandra Zepeda (Mexico) told us how a small company can be made, which at the same time is a school; Cheryl Bains told us the story of Jaspreet Kour (both from Singapore); and Erick de Graaf told us about David, his son (Netherlands). Additionally, Alicia de la Peña (Mexico) told us about the experiences (good and bad) of Mexican parents and grandparents, and also reviewed the translation of the original version of the texts written in English.

The teachers of Community Down (Mexico) gave us their experience about what is known and what should be disclosed. To all of them, our profound gratitude.

The draft became a book thanks to the indefatigable work of Eugenia Huerta. We owe to her and Antonio Bolívar the clarity of the exhibition and to Socorro Gutiérrez the careful preparation of the manuscript.

To Carlos García Ponce we owe the breath since the book was an idea to the present, and now is part of a larger project on disability.

REFERENCES GENERAL

Brogna, P. (comp.) (2009), *Visiones y revisiones de la discapacidad*, México, Fondo de Cultura Económica.

Brown, R.I. (ed.) (2004), *Adult Series, Down Syndrome Issues and Information, Portsmouth, International Down Syndrome Educational Trust*, in <*http://store.dseenterprises.org/collections/ down-syndrome-issues-and-information/adults*>.
Recommended titles in this series:
Brown, R.I. (2004), *Life for Adults with Down Syndrome: An Overview.*
Brown R.I., Brown, P.M., McGinley P. & Takahashi R. (2008), *Community and Independent Living for Adults with Down Syndrome*.
Capie, A., Contardi A., & D. Doehring (2006), *Transition to Employment.*
Crompton, M., & Jackson R. (2003), *Spiritual Well-Being of Adults with Down Syndrome.*
Cuskelly, M., Brown, I., Shearer, J. & Singh B. (2006), *Families of Adults with Down Syndrome.*
Galleguillos-Poza. J., Bidmeade I., Harbord G. & Balnaves,V. (2006), *People with Down Syndrome and the Law (An Australian Perspective).*
Hughson, E.A., & Uditsky, B. (2007), *Inclusive Post-Secondary (Tertiary) Education for Adults with Down Syndrome and Other Developmental Disabilities: A Promising Path to an Inclusive Life.*
McConkey, R., & Timmons, V. (2006), *International and Cultural Aspects of Down Syndrome.*
Velde, B., & Emes, C. (2006), *Recreation and Adults with Down Syndrome.*

Cunningham, C. (2006), *Down Syndrome, An Introduction for Parents and Carers*, Human Horizon Series, 3rd. revised edition, London.

Garhart, C. (2000), *Theories of Childhood: An Introduction to Dewey, Montessori, Erickson, Piaget and Vygotsky*, St. Paul, Minnesota, Readleaf Press.

United Nations Documents (2006), *Convention on the Rights of Persons with Disabilities* in *<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>*

Rosales, C. (2016), *¿Qué hago con un niño con discapacidad?,* 5 vols.: 1. Apóyalo; 2. Conócelo; 3. Atiéndelo; 4. Edúcalo; 5. Aliéntalo, México, Editorial Pax.
Troncoso, M.V., & del Cerro, M.M. (2009), *Síndrome de Down: lectura y escritura*, Fundación Síndrome de Down de Cantabria, in <*http://www.down21.org/libros-online/libroLectura/index.html*>.
World Health Organization (2011), *World Report on Disability* in <*https://www.who.int/disabilities/world_report/2011/report/en/*>

REFERENCES BY CHAPTER

1. What does it mean to live with Down Syndrome?

Biasotto, A., Rasore Quartino, A. & Baccichetti, C. (2011), "Communicating the diagnosis of Down syndrome to families", *Down Syndrome Quarterly*, vol. 13, num. 2, p. 39.
Borthwick, C. (1996), "Racism, IQ and Down's syndrome", *Disability & Society*, vol. 11, num. 3, pp. 403-410.
Clunies-Ross, G. (1986), "Development of children with Down syndrome", *Australian Pediatric Journal*, vol. 22, num. 2, pp. 165-172.
Faragher, R., & Clarke, B., (eds.) (2014), *Educating Learners with Down Syndrome: Research, Theory, and Practice with Children and Adolescents*, London, Routledge.

2. Quality of life and Down syndrome

Andrews, F.M. (1974), "Social indicators of perceived life quality", *Social Indicators Research*, pp. 279-299.
Bertoli, M., Biasini, G., Calignano, M.T., Celani, G. et al. (2011), "Needs and challenges of daily life for people with Down syndrome residing in the city of Rome, Italy", *Journal of Intellectual Disability Research*, vol. 55, num. 8, pp. 801-820.
Borthwick, C. (1996), "Racism, IQ and Down's syndrome", *Disability & Society*, vol. 11, pp. 403-410.
Bovicelli, L., Orsini, L.F., Rizzo, N., Montacuti, V. & Bocchetta, M. (1982), "Reproduction in Down syndrome", *Obstetrics and Gynecology*, vol. 59, pp. 13S-17S.
Brown, R.I. (1994), "Down syndrome and quality of life: Some challenges for future practice", *Down's Syndrome Research and Practice*, vol. 2, num. 1, pp. 19-30.
Brown, R.I. (1996), "Partnership and marriage in Down syndrome", *Down Syndrome Research and Practice*, vol. 4, num. 3, pp. 96-99.
Brown, R.I. (1998), "The effects of quality of life models on the development of research and practice in the field of Down syndrome", *Down Syndrome Research and Practice*, vol. 5, pp. 39-42.
Brown, R.I. (2009), "Friendship for people with Down syndrome" (parts 1 and 2), *Hand in Hand*, Burnaby, Canada, Down Syndrome Research Foundation, Autum.

Brown R.I. (2010), "Adult Education and Intellectual and Allied Developmental Disabilities", in J.H. Stone & Blouin, M. (eds.), International Encyclopedia of Rehabilitation, in: http://sphhp.buffalo.edu/rehabilitation-science/research-and-facilities/funded-research-archive/center-for-international-rehab-research-info-exchange.html
Brown, R.I. (2014), "A lifespan perspective on learning in the context of quality of life", in Faragher, R. & Clarke, B. (eds.), *Educating Learners with Down Syndrome: Research, Theory and Practice with Children and Adolescents*, London, Routledge, pp. 19-39.
Brown, R.I. (2017), "Quality of life-challenges to research, practice and policy", *Journal of Policy and Practice in Intellectual Disabilities*, vol. 14, num. 1, pp. 7-14.
Brown, R.I., & Hughson, E.A. (1993), *Behavioural and Social Rehabilitation and Training*, 2a. ed., Ontario, Captus Press/London, Chapman and Hall.
Brown, R.I., Matthews, B. & Taylor, J. (1999), "Quality of life – ageing and Down syndrome", *Down Syndrome Research and Practice*, vol. 6, num. 3, pp. 111-118.
Brown, I., & Brown, R.I. (2003), *Quality of Life and Disability: An Approach for Community Practitioners*, London, Jessica Kingsley Publishers.
Brown, R.I., Macadam-Crisp, J., Wang, M. et al. (2006), "Family quality of life when there is a child with a developmental disability", *Journal of Policy and Practice in Intellectual Disabilities*, vol. 3, num. 4, pp. 238-246.
Brown, R.I., & Faragher, R. (eds.) (2014), *Quality of Life and Intellectual Disability: Knowledge Application to other Social and Educational Challenges*, New York, Nova Science.
Brown, R.I., Cobigo, V. & Taylor, W.D. (2015), "Quality of life and social inclusion across the lifespan: Challenges and recommendations", special number, "Community care: Past, present and future", *International Journal of Developmental Disabilities*, vol. 61, num. 2, pp. 93-100.
Brown, R.I., Kyrkou, M.R. & Samuel, P. (2016), "Family quality of life", in Rubin, L, Merrick, J., Greydanus, D.E. & Patel, D.R., *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan*, 3rd. ed., Dordrecht, Springer.
Carr, J. (2009), "40 years of life with Down syndrome", *Down Syndrome Quarterly*, vol. 11, pp. 19-25.
Carr, J. (2012), "Six weeks to 45 years: a longitudinal study of a population with Down syndrome", *Journal of Applied Research in Intellectual Disabilities*, vol. 25, pp. 1-9.

Cunningham, C. & Brown, R.I. (2014), "Down syndrome", in Michalos, A.C. (ed.), *Encyclopedia of Quality of Life and Well-Being Research*, Dordrecht, Springer, pp. 1691-1694.
Down Syndrome New South Wales Library Collection in http://www.downsyndromensw.org.au/information .
Goode, D. (1994), *Quality of Life for Persons with Disabilities: International Perspectives and Issues*, Cambridge, Ma. Brookline.
Grantley, J., Brown, R.I. & Thornley, J. (2001), "Challenges to employment: Perceptions and barriers as seen by people with Down syndrome and their parents", *International Journal of Practical Approaches to Disability*, vol. 25, num. 1, pp. 29-35.
Jokinen, N.S., Janicki, M.P., Hogan, M. & Force, L.T. (2012), "The middle years and beyond: Transitions and families of adults with Down syndrome", *Journal on Developmental Disabilities*, vol. 18, num. 2, pp. 59-69.
Jokinen, N.S., Janicki, M.P., Keller, S.M., McCallion, P. & Force, L.T. (2013), "National Task Group on Intellectual Disabilities and Dementia Care Practices. Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia", *Journal of Policy and Practice in Intellectual Disabilities*, vol. 10, num. 1, pp. 1-24.
Lawrence, P.L., Brown, R.I., Mills, J. & Estay, I. (1993), *Adults with Down Syndrome: Together we Can Do it! A Manual for Parents*, The Canadian Down Syndrome Society, Ontario, Captus Press.
Mitchell, D. (2016), *Diversities in Education: Effective Ways to Reach all Learners*, London–New York, Routledge.
Mittler, P. (2015), "The UN Convention on the Rights of Persons with Disabilities: Implementing a Paradigm Shift", *Journal of Policy and Practice in Intellectual Disabilities*, vol. 12, num. 2, pp. 79-89.
Parmenter, T.R. (2014), "Inclusion and quality of life: are we there yet?", in Brown, R.I. & Faragher, R.M. (eds.), *Quality of Life and Intellectual Disability: Knowledge Application to other Social and Educational Challenges*, New York, Nova Science.
Schalock, R. L, Brown, I. Brown, R. I., et al. (2002), "Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts", *Mental Retardation*, vol. 40, num. 6, pp. 457-470.
Schalock, R.L., & Verdugo, M.A. (2012), *A Leadership Guide for Today's Disabilities Organizations: Overcoming Challenges and Making Change Happen*, Baltimore, Brookes.

Sheets, K.B., B.G. Crissman, C.D. Feist et al. (2011), "Practice guidelines for communicating a prenatal or postnatal diagnosis of Down syndrome: Recommendations of the National Society of Genetic Counselors", *Journal of Genetic Counseling*, vol. 20, pp. 432-441.
Turnbull, H.R. (2014), "Quality of life: Four under-considered intersections, in Brown, R.I. & Faragher, R.M. (eds.), *Quality of Life and Intellectual Disability: Knowledge Application to Other Social and Educational Challenges*, New York, Nova Science.

3. Family quality of life – challenges and issues

Beach Center *Family Quality of Life Scale* (2015), University of Kansas, in: https://beachcenter.lsi.ku.edu/
Brown, I. (2012), "Family quality of life: Comparisons of 19 studies in 14 countries". Presented at the World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Halifax, Canada, July 9-14.
Brown, I., & Brown, R.I. (2003), *Quality of Life and Disability. An Approach for Community Practitioners*, London, Jessica Kingsley Publishers.
Brown, R.I. (ed.) (2006), "Special issue on family quality of life", *Journal of Policy and Practice in Intellectual Disabilities*, vol. 3, pp. 209-270.
Brown, R.I., Macadam-Crisp, J., M. Wang et al. (2006), "Family quality of life when there is a child with a developmental disability", *Journal of Policy and Practice in Intellectual Disabilities*, vol. 3, num. 4, pp. 238- 246.
Brown, R.I., Hong, K., Shearer, J., Wang, M. & Wang, S. (2010), "Family quality of life in several countries: Results and discussion of satisfaction in families where there is a child with a disability", in R. Kober (ed.), *Enhancing the Quality of Life of People with Intellectual Disabilities: From Theory to Practice*, Dordrecht, Springer.
Brown R.I., & and Brown, I. (2014), "Family quality of life", in Michalos, A.C. (ed.), *Encyclopedia of Quality of Life and Well-Being Research*, Dordrecht, Springer, pp. 2194-2202.
Cunningham, C., & Brown, R.I. (2014), "Down syndrome", in Michalos, A.C. (ed.), *Encyclopedia of Quality of Life and Well-Being Research, Dordrecht*, Springer, pp. 1691-1694.
Denholm, C. (1991), "The adolescent with Down syndrome", in Down East 91: Learning Together. *Proceedings of the Canadian Down Syndrome Society*, Halifax, pp. 21-23.

Esbensen A.J., Seltzer, M.M. & Greenberg, J.S. (2006), "Depressive symptoms in adults with mild to moderate intellectual disability and their relation to maternal well-being", *Journal of Policy and Practice in Intellectual Disabilities*, vol. 3, num. 4, pp. 229-237.
Faragher, R., & Clarke, B., (eds.) (2014), *Educating Learners with Down Syndrome: Research, Theory and Practice with Children and Adolescents*, Oxford, Routledge.
Kober, R., (ed.) (2010), *Enhancing the Quality of Life of People with Intellectual Disabilities: From Theory to Practice*, Dordrecht, Springer.
National Task Group on Intellectual Disabilities and Dementia Practice, (2012), "My thinker's not working: a national strategy for enabling adults with intellectual disabilities affected by dementia to remain in their com- munity and receive quality supports", in *<http://aadmd.org/ntg/thinker>*.
Schalock, R.L., and Verdugo, M.A. (2014), "Quality of life as a change agent", in Brown, R.I. & Faragher, R.M. (eds.), *Quality of Life and Intellectual Disability: Knowledge Application to Other Social and Educational Challenges*, New York, Nova Science.
Schippers, A. & Van Boheemen, M. (2009), "Family quality of life empowered by family-oriented support", *Journal of Policy and Practice in Intellectual Disabilities*, vol. 6, num. 1, pp. 19-24.
Turnbull, A., Brown, I. & Turnbull, R. (2004), *Families and Persons with Mental Retardation and Quality of Life: International Perspectives*, Washington, DC, American Association for Mental Retardation.
Zuna, N., Brown, I. & Brown, R.I. (2014), "Family quality of life in intellectual and developmental disabilities: a support-based framework to enhance quality of life in other families", in Brown, R.I. & Faragher, R.M. (eds.), *Quality of Life and Intellectual Disability: Knowledge Application to other Social and Educational Challenges*, New York, Nova Science.

4. Friendship for People with Down Syndrome

Brown, R.I., Bayer, M.B. & Brown, P.M. (1992), *Empowerment and Developmental Handicaps: Choices and Quality of Life*, London, Chapman & Hall/Toronto, Captus Press.
Brown, R.I., Brown, P.M., McGinley, P. and Takahashi, R. (2008), *Community Living and Independent Living for Adults with Down Syndrome*, Portsmouth, Down Syndrome Educational Trust.
Burke, C., & McDaniel, J.B. (1991), *A Special Kind of Hero*, New York, Doubleday.

Capie, A, Contardi, A. & Doehring, D. (2006), *Transition to Employment, Down Syndrome Issues and Information*, Portsmouth, Down Syndrome Educational Trust.
Denholm, C. (1992), Developmental needs of adolescents with Down syndrome, in Brown , R.I. (ed.), *Building our Future*, Calgary, National Conference of the Down Syndrome Society.
Greey, M. (2008), "Krystal's big break: Could my daughter, who has Down syndrome, succeed in her first major role?" Reader's Digest, July, pp. 50-56.
Lawrence, P.L., Brown, R.I., Mills, J. & Estay, I. (1993), *Adults with Down Syndrome: Together, We Can Do it!,* York (Ontario), Captus Press–Canadian Down Syndrome Society.
McVilly, K.R., Stancliffe, R.J., Parmenter, T.R. & Burton-Smith, M. (2006a), "Self-advocates have the last say on friendship", *Disability & Society*, vol. 21, num. 7, pp. 693-708.
McVilly, K.R., Stancliffe, R.J., Parmenter, T.R. & Burton-Smith, M (2006b), "I get by with a little help from my friends: adults with intellectual disability discuss loneliness", *Journal of Applied Research in Intellectual Disabilities*, vol. 19, pp. 191-203.
Piaget, J. (1962), *Play, Dreams and Imitation in Childhood*. New York: Norton.
Ryba, K., & Selby, L. (2004) *Information Communication Technology for Adults with Down Syndrome, Portsmouth, International Down Syndrome Educational Trust*, in http://store.dseenterprises.org/collections/down-syndrome-issues-and-information/adults
Stratford, B., & Gunn, P. (eds.) (1996), *New Approaches to Down Syndrome*, New York, Cassell.
The Magnus Family (1995), *A Human Love Story*, Saltspring, British Columbia, Alea Design and Print.
Velde, B., & Emes, C. (2006), *Recreation and Adults with Down Syndrome,* Portsmouth, International Down Syndrome Educational Trust, in http://store.dseenterprises.org/collections/down-syndrome-issues-and-information/adults
Warren, B., Richard, R.J. & Brimbal, J. (2005), *Drama and the Arts for Adults with Down Syndrome – Benefits, Options and Resources, Portsmouth*, International Down Syndrome Educational Trust, in *http://store.dseenterprises.org/collections/down-syndrome-issues-and-information/adults*

Ajuwon, P.M., & Beiber, R. (2014), "Vision impairment and quality of life: Issues from around the world", in R.I. Brown y R.M. Faragher (eds.), *Quality of Life and Intellectual Disability: Knowledge Application to Other Social and Educational Challenges*, New York, Nova Science.
Bird, G., & Buckley, S. (2001), *Number Skills for Individuals with Down Syndrome – An Overview, Hampshire*, The Down Syndrome Educational Trust.
Boyle, C., Scriven, B., Durning, S., & Downes, C. (2011), "Facilitating the learning of all students: The 'professional positive' of inclusive practice in Australian Primary Schools", *Support for Learning*, vol. 26, num. 2, pp. 72-78.
Buckley, S. (2000), *Speech and Language Development for Individuals with Down Syndrome – An Overview*, Southsea, Down Syndrome Educational Trust.
Buckley, S., Bird, G., Sacks, B. & Archer, T. (2006), "A comparison of main- stream and special education for teenagers with Down syndrome: Implications for parents and teachers", *Down Syndrome Research and Practice*, vol. 9, num. 3, pp. 54-67.
Burgoyne, K., Baxter, B. & Buckley, S. (2014), "Developing the reading skills of children with Down syndrome", in Faragher, R. & Clarke, B. (eds.), *Educating Learners with Down Syndrome. Research, Theory and Practice with Children and Adolescents*, Oxford, Routledge, pp. 195-220.
Clarke, B., & Faragher, R. (2014), "Developing early number concepts for children with Down syndrome", in Faragher, R. & Clarke, B. (eds.), *Educating Learners with Down Syndrome. Research, Theory and Practice with Children and Adolescents*, Oxford, Routledge, pp. 146-162.
De Boer, A., Pijl, S.J. & Minnaert, A. (2011), "Regular primary school teachers' attitudes towards inclusive education: a review of the literature", *International Journal of Inclusive Education*, vol. 15, num. 3, pp. 331- 353.
De Boer, A., S.J. Pijl, Post, W. & Minnaert, A. (2012), "Which variables relate to the attitudes of teachers, parents and peers towards students with special educational needs in regular education?", *Educational Studies*, vol. 38, num. 4, pp. 433-448.
De Graaf, G., van Hove, G. & Haveman, M. (2013), "More academics in regular schools? The effect of regular versus special school placement on academic skills in Dutch primary school students

with Down syndrome", *Journal of Intellectual Disability Research*, vol. 57, num. 1, pp. 21-38.
Faragher, R. (2014), "Learning mathematics in the secondary school: Possibilities for students with Down syndrome", in Faragher, R. & Clarke, B. (eds.), *Educating Learners with Down Syndrome: Research, Theory, and Practice with Children and Adolescents*, London, Routledge, pp. 174-191.
Faragher, R. (2014), "Inclusive early numeracy experiences", in Cologon, K. (ed.), *Inclusive Education in the Early Years. Right from the Start, South Melbourne*, Oxford University Press, pp. 381-398.
Faragher, R., & Clarke, B. (2014a), "Mathematics profile of the learner with Down syndrome", in Faragher, R. & Clarke, B. (eds.), *Educating Learners with Down Syndrome: Research, Theory, and Practice with Children and Adolescents*, London, Routledge, pp. 119-145.
Faragher, R.M. (2010), "Developing numeracy to enhance quality of life", in Kober, R. (ed.), *Enhancing the Quality of Life of People with Intellectual Disabilities. From Theory to Practice*, London, Springer, pp. 401- 411.
Faragher, R.M., & Brown, R.I. (2005), "Numeracy for adults with Down syndrome: It's a matter of quality of life", *Journal of Intellectual Disability Research*, vol. 49, num. 10, pp. 761-765.
Faragher, R.M., & Brown, R.I. (2006), "La habilidad en el cálculo en los adultos con síndrome de Down es una cuestión de calidad de vida", *Uno. Revista de Didáctica de las Matemáticas*, vol. 43, julio, pp. 68-78.
Giangreco, M.F., Edelman, S.W., Luiselli, T.E. & MacFarland, S.Z. (1997), "Helping or hovering. Effects of instructional assistant proximity on students with disabilities", *Exceptional Children*, vol. 64, num. 1, pp. 7-18.
Hart, D., Grigal, M., Sax, C., Martínez, D. & Will, M. (2006), "Postsecondary Education Options for Students with Intellectual Disabilities", *Research to Practice Brief*, vol. 45, in Institute for Community Inclusion, https://www.communityinclusion.org/article.php?article_id=178
Jones, E.A., Neil, N. & Feeley, K.M. (2014), "Enhancing learning for children with Down syndrome", in R. Faragher and B. Clarke (eds.), *Educating Learners with Down Syndrome: Research, Theory and Practice with Children and Adolescents*, Oxford, Routledge, pp. 83-115.
Kyrkou, M.R., R. O'Rourke, J.P. Murphy, V.M. Bottroff et al. (2012), "Puberty, menstruation and pain in Australian and Irish females

with Down syndrome", *Journal on Developmental Disabilities*, vol. 18, num. 2, pp. 77-95.
McGregor, G., & and Salisbury, C. (2002), "The administrative climate and context of inclusive elementary schools", *Exceptional Children*, vol. 68, num. 2, pp. 259-274.
Morgan, M.F., Moni, K.B. & Jobling, A. (2009), "Who? Where? What? When? Why? How? Question words – What do they mean?" *British Journal of Learning Disabilities*, vol. 37, pp. 178-185.
Oelwein, P.L. (1995), *Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers*, Bethesda, Woodbine House.
Tait, K. (2014), "Supporting students with intellectual disabilities", in Hyde, M., Carpenter, L. & Conway, R. (eds.), *Diversity, Inclusion and Engagement*, 2nd. ed., South Melbourne, Oxford University Press, pp. 205- 231.
Thousand, J., & Villa, R.A. (2000), "Inclusion", *Special Services in the Schools*, vol. 15, num. 1-2, pp. 73-108.
Torr, J., Strydom, A., Patti, P. & Jokinen, N. (2010), "Aging in Down syndrome: Morbidity and mortality", *Journal of Policy and Practice in Intellectual Disabilities*, vol. 7, num. 1, pp. 70-81.
Troncoso, M.V., & del Cerro, M.M. (2009), *Síndrome de Down: lectura y escritura*, Fundación Síndrome de Down de Cantabria, in https://www.down21.org/libros-online/libroLectura/index.html
Wishart, J.G. (1993), "Learning the hard way: avoidance strategies in young children with Down's syndrome", *Down Syndrome Research and Practice*, vol. 1, num. 2, pp. 47-55.

6. Getting older and enjoying later life

British Institute for Learning Disabilities (2013), "Supporting older families", in http://www.bild.org.uk/resources/ageingwell/olderfamilies/.
British Psychological Society (2015), *Dementia and People with Intellectual Disabilities: Guidance on the Assessment, Diagnosis, Interventions and Support of People with Intellectual Disabilities who Develop Dementia*, Leicester, U.K.
Foundation for People with Learning Disabilities (2015), *Thinking Ahead: A Planning Guide for Families*, London, in https://www.mental-health.org.uk/learning-disabilities/publications/thinking-ahead-planning- guide-families
National Down Syndrome Society (2013), *Aging and Down Syndrome*, New York, NDSS, https://www.ndss.org/?s=Aging+and+Down+Syndrome

Regnard C., Matthews, D., Gibson, L., Clarke, C., & Watson, B. (2003), "Difficulties in identifying distress and its causes in people with severe communication problems", *International Journal of Palliative Nursing*, vol. 9, pp. 173-176.
Royal National Institute for the Blind (2018), *Key Information and Statistics*, in https://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics
Watchman, K. (2001), It's Your Move: *Down Syndrome and Dementia Guide for Medical Practitioners*, in http://www.learningdisabilityand.dementia.org/uploads/1/1/5/8/11581920/its_your_move.pdf
Watchman, K. (2017), *Intellectual Disability and Dementia: A Guide for Families*, London, Jessica Kingsley Publishers.
Watchman, K., Kerr, D. & Wilkinson, H. (2018), *Supporting Derek: A Practice Development Guide to Support Staff Working with People who Have a Learning Difficulty and Dementia*, Glasgow, Pavilion Publishing and Media.
Watchman, K., Tuffrey-Wijne, I. & Quinn, S. (2015), *Jenny's Diary: A Resource to Support Conversations about Dementia with People who Have an Intellectual Disability, London, Alzheimer's Society*, in http://www.learningdisabilityanddementia.org/jennys-diary.html

7. Something on Genetics

Barahona, A., & Piñeiro, D. (1994), *Genética, la continuidad de la vida*, México, Fondo de Cultura Económica.
Breitling, L.P., Yang, R., Korn, B., Burwinkel, B. & Brenner, H. (2011), "Tobacco-smoking-related differential DNA methylation: 27K discovery and replication", *The American Journal of Human Genetics*, vol. 88, num. 4, pp. 450-457.
Brown, R.I., Kyrkou, M.R. & Watchman, K. (in press), "A brief history of Down syndrome – Trends and reflections", in Burack, J., Edgin, J., Abbeduto, L. & Busciglio, J. (eds.), *The Oxford Handbook of Down Syndrome and Development*, Oxford, Oxford University Press.
Chang, K.T., Yi-Jun, S. & Kyung-Tai, M. (2003), "The Drosophila homolog of Down's syndrome critical region 1 gene regulates learning: Implications for mental retardation", *Proceedings of the National Academy of Sciences*, October 16.
De A Moreira, L.M., San Juan, A., Pereyra, P.S. & De Souza, C.S. (2000), "A case of mosaic trisomy 21 with Down's syndrome signs and normal intellectual development", *Journal of Intellectual Disability Research*, vol. 44, num. 1, pp. 91-96.
Del Río, F., & Máximo, L. (1987), *Cosas de la Ciencia*, México, Fondo de Cultura Ecónomica.
Dierssen, M. (2012), "Down syndrome: The brain in trisomic mode", *Nature Reviews Neuroscience*, vol. 13, pp. 844-858.
Estrada, L., & López Beltrán, C. (eds.) (2009), *Naturaleza en evolución, evolución en Naturaleza*, México, Universidad Nacional Autónoma de México.
Francis, D.P., Mielewczik, M., Zargaran, D. & Cole, G.D. (2013), "Autologous bone marrow-derived stem cell therapy in heart disease: Discrepancies and contradictions", *International Journal of Cardiology*, vol. 168, num. 4, pp. 3381-3403.
Haldane, J.B.S. (1927), Possible Worlds, London, Chatto & Windus.
Jenkins, D., & Kirsebom, O. (2013), "The secret of life", *Physics World*, February 7, in https://physicsworld.com/a/the-secret-of-life/
Jiang, J., et al. (2013), "Translating dosage compensation to trisomy 21", Nature, vol. 500, pp. 296-300.
Lazcano, A. (2010), "Historical development of origins research", Cold Spring Harbor Perspectives in Biology, Cold Spring Harbor Laboratory Press, noviembre, in http://cshperspectives.cshlp.org/content/2/11/a002089.full.pdf+html
Lejeune, J., Gautier, M. & Turpin, R. (1959), "Étude des chromosomes somatiques de neuf enfants mongoliens", *Comptes Rendus Hebdomadaires des Seances de l'Academie des Sciences*, vol. 248, num. 11, pp. 1721-1722.
Mégarbané, A., et al. (2009), "The 50th anniversary of the discovery of trisomy 21: The past, present, and future of research and treatment of Down syndrome", *Genetics in Medicine*, vol. 11, pp. 611-616.
Miller, S.L. (1953), "A production of amino acids under possible primitive Earth conditions", *Science*, vol. 117, num. 3046, pp. 528-529.
Oparin, A.I. (1952), *The Origin of Life*. English translation of the 1924 Russian original, New York, Dover.
Piñeiro, D. (2009), "Evolución y método", in Estrada, L. & López Beltrán, C. (eds.), *Naturaleza en evolución, evolución en Naturaleza*, México, Universidad Nacional autónoma de México.
Soberón Mainero, F.X. (2005), *La ingeniería genética, la nueva biotecnología y la era genómica*, México, Fondo de Cultura Economica.

Xionga, Xiao-Peng et al. (2013), "Core small nuclear ribonucleoprotein particle splicing factor SmD1 modulates RNa interference in Drosophila", *Proceedings of the National Academy of Sciences*, September 3.
Wright, D. (2011), Downs: *The History of a Disability*, Oxford, Oxford University Press.
Weinberg, S. (1977), *The First Three Minutes*, New York, Basic Books.

8. Physical characteristics and health issues

Australian Breastfeeding Association, ABA (2018), "Breastfeeding your baby with Down syndrome", in https://www.breastfeeding.asn.au/bf-info/down
Borrel Martínez, J.M., Flórez Beledo, J., Serés Santamaría, A. et al. (2011), *Programa español de salud para personas con síndrome de Down*, in http://www.sindromedown.net/wp-content/uploads/2014/09/90L_downsalud.pdf .
Bull, M.J. (2011), "Health supervision for children with Down syndrome", *Pediatrics*, vol. 128, p. 393.
Davidovich, E., Aframian, D.J., Shapira, J. & Peretz, B. (2010), "A comparison of the sialochemistry, oral pH, and oral health status of Down syndrome children to healthy children", *International Journal of Paediatric Dentistry*, vol. 20, num. 4, pp. 235-241.
Down, J.L.H. (1866), "Observations on an ethnic classification of idiots", London Hospital Reports, vol. 3, pp. 259-262, in http://www.neonatology.org/classics/down.html
Khocht, A., Yaskell, T., Janal, M. et al. (2012), "Subgingival microbiota in adult Down syndrome periodontitis", *Journal of Periodontal Research*, vol. 47, num. 4, pp. 500-507.
Kyrkou, M.R. (2009), "Females with Disability from Puberty to Menopause", PhD thesis, The Flinders University of South Australia.
Mayer-Schönberger, V., & Cukier, K. (2014), *Big Data*, Boston, Mariner Books.
National Down Syndrome Society (2012), in http://www.ndss.org/Resources/Health-Care/
National Task Group on Intellectual Disabilities and Dementia Practice (2012), 'My thinker's not working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in their Community and Receive Quality Supports, in http://aadmd.org/ntg/thinker
Nye, C. (2014), "A Child's Vision", *Pediatric Clinics of North America*, vol. 61, num. 3, pp. 495-503.

O'Dowd, C. (2013), "Evaluating squints in children", *Australian Family Physician*, vol. 42, num. 12, pp. 872-874.

9. Policy Development and Its Application

Bigby, C., M. Knox, Beatle-Brown, J. & Bould, E. (2014), "Identifying good group homes: Qualitative indicators using a quality of life framework", *Intellectual and Developmental Disabilities*, vol. 52, pp. 348-366.
Bradley, V.J., Hiersteiner, D. & Bonardi, A. (2016), "A focus on systems-level outcome indicators", in Schalock, R. & Keith, K.D. (eds.), *Cross-Cultural Quality of Life: Enhancing the Lives of People with Intellectual Disability*, Washington, American Association on Intellectual and Developmental Disabilities, pp. 121-132.
Buntinx, W. (2008), "The logic of relation and the logic of management", *Journal of Intellectual Disability Research*, vol. 52, pp. 588-597.
Christensen, K.M., & Byrne, B.C. (2014), "The built environment and com- munity integration: a review of states' Olmstead plans", *Journal of Disability Policy Studies*, vol. 25, pp. 186-195.
Claes, C., Vandenbusshe, H. & Lombardi, M. (2016), "Human rights and quality of life domains: Identifying cross-cultural indicators", in Schalock, R. & Keith, K.D. (eds.), *Cross-Cultural Quality of Life: Enhancing the Lives of People with Intellectual Disability*, Washington, American Association on Intellectual and Developmental Disabilities, pp. 167-174.
Cummins, R. (2016), "at society's pleasure: The rise and fall of services to people with an intellectual disability", in Jackson, R. & Lyons, M. (eds.), *Community Care and Inclusion*, Edinburgh, Floris Books.
Friedman, T. (2015), "Time for a pause", *New York Times*, January 7, p. A1.
Gómez, L.E., & Verdugo, M.A. (2016), "Outcomes evaluation", in Schalock, R. & Keith, K.D. (eds.), *Cross-Cultural Quality of Life: Enhancing the Lives of People with Intellectual Disability*, Washington, American Association on Intellectual and Developmental Disabilities, pp. 71-80.
Herps, M.A., Buntinx, W.H.E., Schalock, R.L. et al. (2016), "Individual support plans of people with intellectual disabilities in residential services: Content analysis of goals and resources in relation to client characteristics", *Journal of Intellectual Disability Research*, vol. 60, pp. 254-262.

Keith K.D., & Schalock, R.L. (2016), "People speaking for themselves", in Schalock, R. & Keith, K.D. (eds.), *Cross-Cultural Quality of Life: Enhancing the Lives of People with Intellectual Disability*, Washington, American Association on Intellectual and Developmental Disabilities, pp. 35-48.

Manchester, J., Gray-Miceli, D.L., Metcaff, J.A. et al. (2014), "Facilitating Lewin's change model with collaborative evaluation in promoting evidence-based practices of health professionals", *Evaluation and Program Planning*, vol. 47, pp. 82-90.

Mittler, P. (2015), "The UN Convention on the Rights of Persons with Disabilities: Implementing a paradigm shift", *Journal of Policy and Practice in Intellectual Disabilities*, vol. 12, pp. 79-88.

Mostert, R. (2016), "Personal involvement and empowerment", in Schalock, R. & Keith, K.D. (eds.), *Cross-Cultural Quality of Life: Enhancing the Lives of People with Intellectual Disability*, Washington, American Association on Intellectual and Developmental Disabilities, pp. 49-58.

Mpofu, E. (2016), "The evolution of quality of life perspectives in the developing countries of Sub-Saharan Africa", in Schalock, R. & Keith, K.D. (eds.), *Cross-Cultural Quality of Life: Enhancing the Lives of People with Intellectual Disability*, Washington, American Association on Intellectual and Developmental Disabilities, pp. 35-48.

Nussbaum, M.C. (2011), *Creating Capabilities: The Human Development Approach*, Cambridge, Ma, Harvard University Press.

Rapley, M. (2004), *The Social Construction of Intellectual Disability*, Cambridge, Cambridge University Press.

Reinders, H., & Schalock, R.L. (2014), "How organizations can enhance the quality of life of their clients and assess their results: The concept of QOL enhancement", *American Journal of Intellectual and Developmental Disabilities*, vol. 119, pp. 291-302.

Schalock, R.L., & Keith, K.D. (2016), "Setting the cross-cultural quality of life agenda to enhance the lives of people with intellectual disability", in Schalock, R. & Keith, K.D. (eds.), *Cross-Cultural Quality of Life: Enhancing the Lives of People with Intellectual Disability*, Washington, American Association on Intellectual and Developmental Disabilities, pp. 203-218.

Schalock, R.L., & Luckasson, R. (2014), *Clinical Judgment*, 2nd. ed., Washington, American Association on Intellectual and Developmental Disabilities.

Schalock, R.L., & Verdugo, M.A. (2012a), "A conceptual and measurement framework to guide policy development and systems change", *Journal of Policy and Practice in Intellectual Disabilities*, vol. 9, pp. 70-79.

Schalock, R.L., & Verdugo, M.A. (2012b), *A Leadership Guide for Today's Disabilities Organizations: Overcoming Challenges and Making Change Happen*, Baltimore, Brookes.

Schalock, R.L., and M.A. Verdugo (2013), "The transformation of disability organizations", *Intellectual and Developmental Disabilities*, vol. 51, pp. 273-286.

Schalock, R.L., Verdugo, M.A., Gómez, L.E. & Reinders, H. (2016), "Moving us toward a theory of individual quality of life", *American Journal on Intellectual and Developmental Disabilities*, vol. 112, pp. 1-12.

Schippers, A., Zuna, N. & Brown, I. (2015), "A proposed framework for an integrated process of improving quality of life", *Journal of Policy and Practice in Intellectual Disability*, vol. 12, pp. 151-161.

Shogren, K.A., Luckasson, R. & Schalock, R.L. (2015), "Using context as an integrative framework to align policy goals, supports, and outcomes in intellectual disability", *Intellectual and Developmental Disability*, vol. 53, pp. 367-376.

Stancliffe, R.J., Arnold, S.R.C. & Riches, V.C. (2016), "The supports paradigm", in Schalock, R. & Keith, K.D. (eds.), *Cross-Cultural Quality of Life: Enhancing the Lives of People with Intellectual Disability*, Washington, American Association on Intellectual and Developmental Disabilities, pp. 35-48.

Thompson, J.R., Schalock, R.L., Agosta, J., Teninty, L. & Fortune, J. (2014), "How the supports paradigm is transforming service systems for per- sons with intellectual disability and related developmental disabilities", *Inclusion*, vol. 2, pp. 86-99.

Turnbull, H.R., & Stowe, M. (2014), "Outcomes-driven policy development", *Intellectual and Developmental Disabilities*, vol. 54, pp. 120-134.

Verdugo, M.A., Schalock, R.L., Keith, K.D. and Stancliffe, R.J. (2005), "Quality of life and its measurement: Important principles and guidelines", *Journal of Intellectual Disability Research*, vol. 49, pp. 707-717.

Verdugo, M.A., Navas, P., Gómez, L.E. & Schalock, R.L. (2012), "The concept of quality of life and its role in enhancing human rights in the field of intellectual disability", *Journal of Intellectual Disability Research*, vol. 56, pp. 1036-1045.

Wehmeyer M.L. (ed.) (2013), *The Oxford Handbook of Positive Psychology and Disability*, Oxford, Oxford University Press.

10. International issues – families in action

Buckley F., & Buckley, S.J. (2008), "Wrongful deaths and rightful lives screening for Down syndrome", *Down Syndrome Research and Practice*, vol. 12, num. 2, pp. 79-86.

INEGI (2010), Discapacidad, porcentaje de la población con limitación en la actividad según tipo de limitación para cada entidad federativa, in http://www3.inegi.org.mx/sistemas/sisept/default.aspx?t=mdis03&s= est&c=27716

Natoli, J.L., Ackerman, D.L., McDermott, S. & Edwards, J.G. (2012), "Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995-2011)", *Prenatal Diagnosis*, vol. 32, num. 2, pp. 142-153.

Thompson, R. H. (ed.) (2009), *The Handbook of Child Life: A Guide for Pediatric Psychosocial Care*, Springfield, Charles C. Thomas Publisher.

United Nations Documents (1948), Universal Declaration of Human Rights, in https://www.un.org/en/universal-declaration-human-rights/index.html

United Nations Documents (1993), Standard Rules on the Equalization of Opportunities for Persons with Disabilities, in https://www.un.org/development/desa/disabilities/standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities.html

United Nations Documents (2001), Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, in <https://www.un.org/development/desa/disabilities/comprehensive-and-integral-international-convention-to-promote-and-protect-the-rights-and-dignity-of-persons-with-disabilities-ares57229-2.html >.

United Nations Documents (2001), World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, in https://www.un.org/en/durbanreview2009/pdf/DDPA_full_text.pdf

United Nations Documents (2004), International Norms and Standards Relating to Disability, in http://unipd-centrodirittiumani.it/public/docs/International_Norms_and_Standards_Relating_to_Disability.pdf

United Nations Documents (2006), Convention on the Rights of Persons with Disabilities in https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

This book is written for parents, grandparents, medical staff and caregivers of people with Down syndrome; undergraduate students and young researchers in the field of intellectual disabilities, to give a broad coverage of Down syndrome, showing the latest advances and the changes in its perception, based on practice, personal experience and research.

Down syndrome is discussed throughout the lifespan - from birth to old age, in the family and community. The issues of friendship, school and employment as well as health in its broadest sense and the challenges of ageing are reviewed. The application of policies based on both the Convention on the Rights of Persons with Disabilities and the concept of quality of life is also considered. Genetics is often misunderstood, so a simple explanation is given in terms of a condition that occurs naturally as a result of billions of years of evolution.

The variability of people with Down syndrome is exemplified with cases from various parts of the world that have been successful in their lives and in their activities. The book is summarised with an optimistic photo essay.
It contains an abundant bibliography both historical and recent.

This book, originally published in Spanish, was translated to benefit a wider range of readers in need of a rigorous exposition of Down syndrome in accessible terms, including those whose English is their second languaga.

ABOUT THE AUTHORS

Manuel I. Guerrero is a scientist and writer of popular expositions of scientific topics. His first grandson was born with Down syndrome.

Roy I. Brown is an emeritus professor, educator, and leader of international programmes to support persons with intellectual disability. His work is known worldwide and has received much recognition from professional and academic organisations.

ISBN 9781082060106

90000

9 781082 060106