



**Medicus Mundi
Switzerland**

Health for all

MMS Bulletin #168

Decolonization in international health cooperation: Are we ready for it?

Reflexions from a father

**What does the International Women's Day
2024 Theme: 'Inspiring Inclusion' mean to
my daughter, a 16-year-old who has been
living with epilepsy since she was 8 months
old?**

By Dr. Venkatraman Chandra-Mouli

The campaign theme for the International Women's Day (IWD) for this year is Inspiring Inclusion (I): The IWD website notes that 'When we inspire others to understand and value woman's inclusion, we forge a better world. And when women themselves are inspired to be included, there is a sense of belonging, relevance, and empowerment.'



Photo: © Chandra-Mouli

Walking with my dog in the little forest near our home in Geneva, I reflected on how the IWD theme related to a young woman close to me - my 16-year-old daughter Sarita who has lived with epilepsy since she was eight months old. I decided to ask her. This led to an interesting discussion on what she understood by the words inclusion and exclusion, and what her perceptions and experiences of being included and excluded were.

I have been writing and sharing updates on Sarita's health with relatives, friends, and colleagues for years (Chandra-Mouli V. 2013, 3.) (Chandra-Mouli V. 2013, 4.) I asked Sarita if I could write up what we had discussed about the IWD theme. She agreed immediately and proposed that we ask her mother for her inputs as well. We did that. So here we are – a reflection on what the IWD theme means to us.

A few words about Sarita

Sarita was born in Geneva in August 2007, after an entirely normal pregnancy and childbirth. She seemed perfectly healthy. Out of the blue, when she was eight months old, she woke us up one night convulsing in her bed. Over the months, we learned that the convulsions were due to focal cortical dysplasia, meaning that a part of her brain had not developed as it should have, and was triggering convulsions. The good news was that the convulsions were not due to a cancerous tumor, an infection, a metabolic condition, or a degenerative condition.

The bad news was that the convulsions were occurring several times a day and were not responding to medication. In 2009, when she was a little under two years old, Sarita had an operation to remove the dysplastic tissue at the University Hospital, Geneva. Sadly, the operation was only partially successful. We then arranged for her to have a second operation – a year later - at the Cleveland Clinic, one of the premier hospitals in the USA. With the second operation, the number and severity of Sarita's convulsions have decreased but she still needs anti-epileptic medication. Even with that, she is not entirely convulsion free, especially at night. Over the years, her neurologists have tried different anti-epileptics medicines to try to achieve better convulsion control. Alongside that, Sarita has received physiotherapy, occupational therapy, speech therapy and psychological support.

Sarita has had a serious health problem since she was eight months old. Without a doubt this has had a negative effect on her life in terms of physical activities, educational performance, and emotional wellbeing. But overall, Sarita has coped with her condition with courage – and even some humour - and moved on with her life. She speaks English, French and Spanish with similar levels of fluency. Her speaking abilities are better than her reading and writing, but the latter are improving. She took ballet dance lessons for many years and is now taking classical music singing lessons. She is interested and concerned about what is happening in the world. And, sharing my home office during the COVID-19 years and beyond, has influenced her. One of her campaigns as a class representative is for free menstrual products in her school.

One of our big fears as parents was that Sarita would have a hard time making and keeping friends. Thankfully, we were wrong. Today, Sarita has friends from the school she is in and from the schools she was in. She gets WhatsApp calls and messages, goes to birthday parties and gets together with friends once in a while, to hang around.

Sarita is attractive, positive, curious, friendly, loving and giving. She is a full-fledged teenager - conscious of her looks, attached to her screens, and with distinct likes in dress, music, and food. Most importantly, she has a growing sense of herself and her place in her family, in her school, in her community and the wider world.

A few words about us, her parents

Sarita is much loved by her immediate family in Geneva (my wife, myself, my son, and his wife who live nearby, and Ayleen Arante – a wonderful Filipina woman who has helped us care for Sarita since she was four months old), and by her extended family in India, Spain and elsewhere. She is at the center of our lives. We have done everything in our power and more

to get her the best care possible, and to encourage and support her to grow and develop to her full potential, and most importantly to be happy. But Sarita has not become who she is because of the miracles of modern medicine and a caring family with the ability to support her alone. It is because of the Swiss Government's health, education, and social protection systems that have empowered her, and enabled her inclusion in three crucial spheres of her life – going to school, using public transport, and preparing for a sexual and reproductive life.

Three systems that have empowered Sarita and fostered inclusion

Actions taken to enable Sarita to stay in school

When Sarita was two years old, she started going to the crèche in our commune Chambésy - *Les Pitchounets*. This was the time in her life when she was having many convulsions daily. The teachers and the crèche administration agreed to take her in after securing funding from the commune authorities to engage an adult to protect her from being hurt on the premises. This meant being physically next to her, to 'grab' her if she had a convulsion and thus to prevent her from falling. Ayleen Arante, whom I mentioned earlier, took on this challenging task and did it brilliantly. Sarita spent three years at *Les Pitchounets* and enjoyed the social contact and the activities. We have wonderful photos of that period of a happy little girl with her classmates.

When Sarita was five years old, she joined the *Ecole de Valérie*, the government primary school in our commune. By this time, her convulsions were under better control through they did occur from time to time. For the first year or so, all seemed well. From the second year onwards, we learned from her teachers that she was falling behind the others. Following discussions with her teachers and the school administration, they decided to request for a teacher-aide to sit beside her and provide her with dedicated support. Despite these efforts and our efforts at home, the gap between her and those of her peers begin to grow. Sarita developed a stammer. She told us that she was being set aside by her teachers and mocked by her classmates for 'being a baby'. When we went to pick her up after school, she looked sad and was always by herself. A child who was once happy to go to school did not want to do so anymore. It was heartbreaking for us as parents.

When the school administration and the Geneva Canton authorities proposed that we move Sarita to a primary school for children with special learning needs, we resisted it because we so wanted her to be with 'normal' children. But the decision was made to move her to *Ecole Ami Argand*. The transition was managed very well – her learning and medical records were transferred, and the teaching and nursing staff briefed. *Ecole Ami Argand* had a separate section for children with special learning needs, set within a bigger school for children without such needs. The objectives of this stream of education were threefold - to support children develop academically according to their capacity, to contribute to their psychosocial development, and

to develop their autonomy and independence. The school had a well-trained, experienced and committed team of teaching and complementary professionals. They worked to achieve these objectives with classroom teaching and a range of extracurricular activities including regular field visits within and outside Geneva (I have used past tense here but the school is still very much operational).



Photo: © Chandra-Mouli

Sarita thrived in this environment. She developed on all fronts and made friends for the first time. After five years at the *Ecole Ami Argand*, Sarita was ready to move to middle school. She joined the *Cycle de Budé* - which is also a school within a school for children with special learning needs. Here too she continued to make progress on all fronts, but specially in becoming more autonomous (as discussed further in the next section).

In 2023, when she was 15, Sarita graduated out of the *Cycle de Budé* - after two years there - to join the *Société genevoise pour l'intégration professionnelle des adolescent-e-s et des d'adultes*, which is geared to preparing young people like her with special needs, to choose a line of work and to help them define next steps in getting there. Sarita is blossoming here.

To sum up, like children in so many countries, Sarita could have been excluded from education because she has different learning abilities (UNESCO 2021). But she has – and continues to have – a superb educational experience because of Switzerland's commitment to including all learners in its educational system, and to its well-resourced and networked systems with able

and committed professionals to respond to those with and without special needs (Canton of Geneva. What is an inclusive school?).

Actions taken to facilitate Sarita's use of public transport

Because of her special needs, Sarita was entitled to transport support to and from her school. Through the five years she was in the *Ecole Ami Argand*, she along with some other children were picked up and dropped home by taxi. The service was provided by a two-person team, vetted, and engaged by the authorities. We were formally introduced to the team. We exchanged phone numbers with them and contacted them when needed, e.g., if there was a delay or a change of plans. Over time we got to know them well and they became part of Sarita's 'village.'

The transport support service continued in the two years that Sarita spent in the next step in her education – in the Cycle de Budé. While providing her and other students with transport support, the school worked to wean them off it. As part of its strategy to build autonomy, the school taught the children how to use public transport. This was done in a structured manner over several weeks, as follows. Firstly, we parents were informed about what was planned and our permission was secured. Secondly, the teachers worked with Sarita and with us to chart out the best bus route for her to take. She had a 30-minute ride in all but needed to change a bus. Thirdly, during the school day a teacher made the journey with Sarita by bus to our home, touched the front door but did not enter, and then returned with her to school. He did that four-five times. Fourthly, he asked her to make the journey on her own with the understanding that he would be in the bus but not with her. She would be able to see him and to ask him for help if needed. This happened four-five times. Fifthly, he asked Sarita to make the journey on her own and said that he would follow her on the next bus. This too happened four-five times. Sixthly he asked Sarita to make the journey on her own and to call him on the phone if she had a problem. Finally, after a few independent trips like this, the school certified that Sarita had passed the test and was approved to travel independently. This was a red-letter day in her life. We went with her to get her an annual bus pass and had a celebratory meal at a restaurant of her choice - Burger King's. Since that day, Sarita has declined the offer of the free protected taxi service that she is entitled to, and travels by public transport. (I must add that her mother drops her off in the mornings when she can, to make it a little easy for her and to have the opportunity to catch up with her.)

Sarita sees travelling on her own by public transport as a badge of honour, and as a testimony to her growing up and becoming independent. Thankfully, she only rarely has convulsions during the day and when she does, she can almost always feel them coming and sits on the ground to avoid falling. Her teachers convinced her and us that the occasional risk of a convulsion should not be grounds to prevent her from moving independently or using public transport. Their position – which we fully agreed to - is that she should get the care she needs

to have the best convulsion control possible and move ahead with her life. They have asked her to wear a badge around her neck saying that she has epilepsy and trust that the bus drivers - and other members of the public - who are trained to provide first aid come to her assistance if needed. Thankfully this has not been needed thus far.

To sum up, through a carefully thought through and executed strategy, Sarita's school in association with the public transport service, empowered Sarita to use public transport - an important aspect of her inclusion in society as an autonomous individual.

Actions taken to prepare her for a sexual and reproductive life in the future

Switzerland has an excellent school-based sexuality education programme (Federal Office of Public Health, Switzerland. 2018). The approaches used to deliver sexuality education vary between the regions of the country. In the French-speaking part of the country, sessions are delivered by sexuality education experts in conjunction with teachers. These sessions include briefing and engaging parents to complement the school-based teaching with discussions at home, a series of structured teaching sessions conducted over time during the students' school careers beginning with information provision, and then going on to question-answer sessions, discussions on topical issues such as consent, and field visits to providers of services. Sarita and other students in Switzerland's alternative education track for children with special needs received the very same sexuality education as all other children and adolescents do.

We complemented the school-based education with reading and discussion at home. I introduced Sarita to the wonderful book: *Questions children ask and how to answer them*, which I discovered with my son many years ago. Friends from the USA presented her two other books that she loved: *The care and keeping of you: The body book for younger girls*, and *The care and keeping of you: The body book for older girls*. My wife and I would take a chapter such as 'Flat chest to new breasts' and read it aloud with her after dinner followed by a lively discussion. So, at school and at home Sarita was being prepared for a future sexual and reproductive life with open and frank – and fun-filled – discussion.

Moving to another issue, in the last few months, Sarita has transitioned from pediatric to adult epilepsy care at the University Hospital, Geneva. As part of this transition process the pediatric and adult teams carried out a number of tests and met with us to discuss the findings and their implications. They provided us with information and answered the questions we had listed including two that Sarita had: 'If I am pregnant in the future, could the anti-epilepsy medicine that I am on, harm my baby?' and 'If I have a child in the future, could I pass on my epilepsy to my child?'. The doctors took Sarita and her questions seriously and answered them openly and

frankly. One of the doctors also suggested that it would be useful for Sarita to see a gynecologist and get information and advice about contraception so that she is ready to use it in the future.

To sum up, in many parts of the world, the sexual and reproductive needs and wants of young people and even adults with disabilities are not acknowledged or even obstructed (Carter, A., et al. 2022). Providing children and adolescents with special needs, the same sexuality education that all children and adolescents in the country get, clearly recognizes that they are sexual beings too, despite their different abilities. And in providing them with sexual and reproductive health services, recognizes that they have the same entitlements to have sex and to services and commodities they need to keep them safe and well. The educational authorities and the teachers are very well aware that students with special needs are more vulnerable than their peers without special needs, to violence and abuse. They believe – like we do - that empowering them with information, education, services, and commodities is an important part of an overall strategy that to protect them and build their autonomy to make and act on well-informed and well-through through decisions.

But all this has not happened only because Switzerland is rich. It is because of a foundational commitment to equality which is enshrined in laws, policies, and regulations, and is translated into workplans, budgets and ultimately to services that are responsive to the differing needs of people.

Closing

Without a doubt, Sarita has been included – and feels included - in education, in using public transport services, and in preparing for a healthy, happy, and productive life including a sexual and reproductive life. She has lived in Switzerland for all her life, and we dare say that she takes this for granted. As parents, we do not. We are aware that this is not the reality in so many parts of the world. It would be easy to say that the inclusive systems and structures in Switzerland are possible because it is wealthy. But all this has not happened only because the country is rich. It is because of a foundational commitment to equality which is enshrined in laws, policies, and regulations, and is translated into workplans, budgets and ultimately to services that are responsive to the differing needs of people. In a nutshell, a stated commitment to equality is matched with investment and actions to ensure that those with special needs can be as equal as possible to all.

That is why the IWD theme resonates with Sarita's life: "...when women – and girls - themselves are inspired to be included, there is a sense of belonging, relevance, and empowerment.'

References

1. International Women's Day, March 8. <https://www.internationalwomensday.com/>
2. Chandra-Mouli V. Ma fille souffre d'épilepsie: Le point de vue d'un père et mari 1/2 (My daughter suffers from epilepsy: The point of view of a father and a husband). *Epi-Info*, 2013, 3. <https://drvchandramouli.com/wp-content/uploads/2021/06/Newsletter-article-Epi-Suisse-3-2013.pdf>
3. Chandra-Mouli V. Ma fille souffre d'épilepsie: Le point de vue d'un père et mari 2/2. (My daughter suffers from epilepsy: The point of view of a father and a husband) *Epi-Info*, 2013, 4 <https://drvchandramouli.com/wp-content/uploads/2021/06/Newsletter-article-Epi-Suisse-4-2013.pdf>
4. UNESCO. Disability inclusive education and learning, 2021: <https://learningportal.iiep.unesco.org/en/issue-briefs/improve-learning/disability-inclusive-education-and-learning>
5. Canton of Geneva. L'école inclusive, c'est quoi? (What is an inclusive school ?) F: <https://www.ge.ch/dossier/ecole-plus-inclusive-geneve/presentation-ecole-inclusive/ecole-inclusive-c-est-quoi> E: <https://www.edk.ch/en/education-system-ch/compulsory/special-needs>
6. Federal Office of Public Health, Switzerland (2018): <https://www.bag.admin.ch/bag/en/home/gesund-leben/gesundheitsfoerderung-und-praevention/praevention-fuer-kinder-und-jugendliche/sexualaufklaerung.html> (Preventive Health for Children and Young People – Sexuality Education) Health for children and adolescents (admin.ch)
7. Carter, A., Strnadová, I., Watfern, C. et al. The Sexual and Reproductive Health and Rights of Young People with Intellectual Disability: A Scoping Review. *Sexuality Research and Social Policy* 19, 372–390 (2022). <https://doi.org/10.1007/s13178-021-00549-y>



Dr. Venkatraman Chandra-Mouli (Chandra) Formerly - Scientist, Adolescent Sexual and Reproductive Health of the Department of Sexual and Reproductive Health and Research, World Health Organization (which includes the UNDP/UNFPA/UNICEF/WHO/World Bank Human Reproductive Programme). Currently - I continue to work with a number of organizations on adolescent sexual & reproductive health and rights, but not for any one of them. Email: chandramouli@bluewin.ch

Kontakt

Deutschschweiz

Medicus Mundi Schweiz
Murbacherstrasse 34
CH-4056 Basel
Tel. +41 61 383 18 10
info@medicusmundi.ch

Suisse romande

Medicus Mundi Suisse
Rue de Varembé I
CH-1202 Genève
Tél. +41 22 920 08 08
contact@medicusmundi.ch

Bank details

Basler Kantonalbank, Aeschen, 4002 Basel
Medicus Mundi Schweiz, 4056 Basel
IBAN: CH40 0077 0016 0516 9903 5
BIC: BKBBCHBBXXX