

Is my daughter a genius?

Managing the education of a child with Down Syndrome

Arun Ram
Department of Mathematics and Statistics
University of Melbourne
Parkville, VIC 3010 Australia
aram@unimelb.edu.au
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Abstract.

This paper is an identity narrative of a parent with a child with Down Syndrome. It explores theory and practice for the education of the child in a modern and changing context. What are the possibilities and challenges, and what are the realities? What are the ways forward?

This paper was given in a presentation at the conference "Honoring the Child, Honoring Equity 14, Embracing diverse identities" held at the University of Melbourne Graduate School of Education, 21-22 November 2014. I would like to thank the organisers for presenting such a stimulating conference, the other presenters and participants of the conference for teaching me so much about this field so quickly, the program committee for truly embracing diversity by including me as a presenter, and Gigliola Aru, Zajt Daugherty, Jae and Marianna for references, insightful conversations and support through this adventure of preparing and giving this paper and this presentation.

1. The Evolving Theory to be put into Practice

- How can we explore identities in a changing world (including but not limited to gender, culture, religion, linguistics, ability and environment)?

If we are interacting with our society we are always exploring our identities and the identities of those around us. If our society is changing then we are living in a changing world. We can try to minimise the changes in the way we interact with society or we can choose to recognise and explore them. The best way is to find a balance between these restrictions and these explorations. The most effective balance provides a basis for embracing change and implementing new ideas without bringing down the basic structures holding up the building, at least not all at once. Parts of the system must be renovated for suitable living before bringing down the other, older, part of the house.

- What are the narratives of and for diverse identities?

My narrative is about a child with Down Syndrome, the planning and implementation of her education.

- How can we explore localised identities in globalised contexts?

The primary difficulty is one of communication. How will she implement her communications with the global community? Global, in our framework, indicates any community

outside the home.

- What are the challenges to exploring diverse identities with young children?

The challenges are social ones. Social, by its very nature, means forming a group, which, by nature of a group has isolated itself in some way, thus restricting diversity. How is the child to find her place in a social environment? In almost all the natural social settings the child experiences outside the home, her place in the social environment is determined by the way that she communicates. Shaping this communication is the form in which the educator or friend can be most helpful for the child for whom the standard mechanisms are not as easy to implement.

The very real analogy is the adult who does not speak French being placed into a rural French village. How will he establish his identity, which is fundamentally diverse from that of the community he has entered because he does not speak French, in the context of the society of the village in which he is placed? How will the members of the village find a way to communicate with this new individual?

- What are the ways forward in policy and practice?

The ways forward in policy and practice are through education and communication. The constant in policy and practice is the challenge of effectively allocating resources. Too often we forget that time and energy must also be factored into the formulas for allocation of resources.

- How are educators exploring children's identities in everyday practice? What are the possibilities and challenges?

If educators are not continually extending their education and their knowledge then they are not exploring children's identities. There is a lot to learn, and any active thinking about what is learned will have an effect on everyday practice.

The possibilities are always endless. If at any moment there are insufficient options available then either the working parties are not willing to place effort into generating ideas or have the wrong attitude. The more real issues always centre around balancing the energy, effort and resources to put ideas into action.

The challenges always, in one form another, are about the allocation and placement of resources, whether it be money, attention, or time. The issues in placement of resources are usually about whether the resources should be focused in a small area to provide excellent service in that area, or to distribute the resources to provide partial services over a wider area. The disadvantage of placing resources in a small area is that those who could benefit from them must somehow place themselves in that area. Another disadvantage is that locating a large population in a small area minimises diversity.

- What theories help to recognise and support multiple identities for children and families in research, policy and practice?

Home focused cultures and modern Western cultures are more and more active in recognising and supporting multiple identities in a single mainstream. In a warm and loving home, a special needs child will naturally find a social place and a communication mechanism which provides for needs and, at the same time, provides independence and progression of skills. The community inside the home is small enough that there will be natural education about the mechanisms and

features of the person with special needs. At some point these "special needs" become less of a difference and more just an expression of the personality and characteristics of that individual. All members of the family unit are individuals with their own personalities, talents, needs, and communication mechanisms and it becomes hard to distinguish the differences of the special needs member from the differences of any other individual in the framework.

- What are the identity narratives for educators working with curriculum and policy documents?

The identity narratives for educators working with curriculum and policy documents are education and communication. Parents and family members, and most importantly, the child, are usually uneducated in regard to the curriculum and policy documents. The family often has the feeling that it is very difficult to get this information and the gratitude to those who provide it clearly and efficiently is immense. Only with a knowledge of the forces at play can suitable and effective solutions be constructed. It is immensely important to make an effort to communicate the content of the curriculum and policy documents to the child. While the child may not respond, when the child does, this new information is invaluable in designing an effective and positive environment for the child. To a large extent, the more active the child can be in the design, the more effective the design is.

- How can parents and families share their identity narratives?

Parents and families can share their identity narratives through opportunities for education of the communities outside the home. This education most effectively takes the form of explanations to individuals which can provide a basis for positive interactions with the special needs child who needs a communication framework which is likely different from the societal norms.

The first step is for the teacher or the friend to communicate with the child. This step is often aided by a family member (member of the home unit) providing helpful insight in effective communication processes. In spite of the usual tendencies and conventions, it is actually unnecessary for the child to communicate back in order for the teacher or friend to successfully communicate with the child. It is often a challenge to encourage teachers and friends to continue the communications when they are one sided but experience indicates that this is the most important step in the success of the process.

The second step is to enable the child to communicate responses. This step is most effectively accomplished by the small cues provided by the child. Since these cues are often different from the expected ones, the teacher or friend must be receptive and open to novel communicative cues. Once these cues are beginning to be received by the teacher they will be magnified by encouragement and response. When this happens communication has begun and it only remains to strengthen the connections and improve the mechanisms.

If the child is communicating then the child has begun to share their own identity narratives and the necessity for the parents and families to share their narratives changes function. They can only provide further hints in progressing the communication between the teacher and the child, and satisfy their own need to communicate their experience. This last form of sharing is less about the needs of the child and more about the needs of the parent (which are also important and need attention).

2. The Practice of the Evolving Theory

Marianna Ram was born on 9 October 2002, in Madison Wisconsin, USA. Her father is a professor of mathematics and her mother is a retired violinist (formerly second violinist of the Pro Arte String quartet, in residence at the University of Wisconsin, Madison). Marianna's parents began to learn about the features of Down Syndrome on the day that Marianna was born. Like most members of their community, except for knowing the existence of the syndrome, they had had no education about it. As a university professor broadly educated in science, Marianna's father knew that it was genetic and was reflected in an extra chromosome, but he had no additional knowledge about it.

An amazing amount of information, and misinformation, came in in the first few months after Marianna's birth. Being a scientist by profession, the amount of information ingested in these few months was probably more than the norm for parents with a new child with Down Syndrome, as he spent significant time at the university library reading resources to learn about it. After a few months the, correct, conclusion was that, for the most part, we should proceed in raising the child as we would with any other child, with love, encouragement, attention and diligence. Except for a few possible physical health issues that one should be watchful for, it was clear that all evidence pointed towards a continued development, and that the progression of this development was not well understood, or at least well documented, in the literature. We would just have to work day by day, taking our cues from the child herself.

Her father, as he would have done with any daughter, began a routine where he read to her, every evening for 30 minutes. He would hold her in his lap and read, pointing to the words as he went. The books were chosen from standard baby books available from the local libraries and bookstores. Sometime during the first few months, her parents noticed that Marianna provided small expressions of comprehension of language and significant comprehension of situations and routine. There was already constant work in the daily routine for efforts such as trying to strengthen the very common muscular challenges from hypotonia.

Marianna did not speak until the age of 5. Even before she was able to walk she would scoot around on the floor on her bottom, and she had learned enough that we could dump the foam letters on the other side of the room and she very much enjoyed the game of fetching us the letter we asked for. At home, she worked intensely with her mother to learn sign language to help with the frustrations of communication. Marianna would roll her eyes with that "my Daddy is so stupid" look when her father did not understand what she was signing because he had been at work earning a living instead of practising sign language. After many months of parents' sore backs Marianna started to walk on her own at age 2. At age 3, when Marianna's father did not understand a word she was signing she went to the bookshelf pulled out the book she wanted, found the page she wanted and pointed to the word that corresponded to the sign that her father did not understand. She didn't talk, but she had forcefully demonstrated that she could read.

The day before Marianna's first day at prep her father made sure to go to the school to meet the new teacher. Six months later the teacher told Marianna's parents, "She didn't respond to me for a month. I just kept telling myself that you told me that she understands every word I say to her." After 3 months at prep Marianna and her teacher already had a routine where a very proud Marianna would accompany her teacher to help set up for PE. Apparently they had great fun together during these setup sessions. It was perfectly possible for them to communicate with each other with only her teacher speaking ordinary English and with Marianna using gestures and a few

selected words. But Marianna was now participating as a member of a social community outside the home.

Today Marianna is in grade 5, mainstreamed in a public primary school in Melbourne Australia. She reads well, is able to write at about a grade 2 level, and comprehends everything that happens in class. She speaks in class, but every time that she talks is akin to the effort her father experiences when he is in France and has to speak in French. The words come out slowly and carefully. Most conversations simply pass by at a pace which makes it unrealistic for a tentative, uncertain, French communicator to participate effectively in the conversation even though he understands quite well what is being said. Anyone who speaks to Marianna and requires a response must wait until the words are carefully formed and come out, just as those poor Parisians painfully wait for her father to provide information.

At this stage, Marianna's father needs to make decisions on the execution of Marianna's transition after primary school. Just as he was ignorant before Marianna was born, the teachers and educators that might play a role in her secondary education have minimal education about Down Syndrome, its features, and effective pedagogical practice in this context. The obligation for education of Marianna's mentors is slowly transitioning from her parents to herself: she must teach her teachers about genetics, about what it feels like to talk and perform in a social setting and what are effective methods for making progress in her future education. But the tables have not turned completely yet, and her father is actively collecting information, educating himself about the system and the way it functions, and educating and communicating with Marianna's possible future school teachers.

3. Conclusions and apologies

If the teachers are educating the parents about curriculum and policy and the parents are educating the teachers about how to communicate with the child then both the policy and practice are moving forward. When the child is communicating then the child has begun to share their own identity narratives.

This article is written by a successful scientist addressing a community he is unfamiliar with. Although he has great experience in the subject, he has little experience with the society of the subject and his scholarly morality finds it horrific that he is unable to provide appropriate references to the scholarly literature in the field and appropriate analysis of alternative perspectives treated in the scholarly literature. However, there is nothing that can be done at this moment except to be honest about this deficiency. The alternative is to not share the identity narrative, a path that he takes all too often. It is an opportunity for him to experience exactly how Marianna so often feels.

4. Appendix: Education of the schoolyard

It was the first few weeks of term 1 at Carlton Gardens Primary School where Marianna was starting at prep. I can't be sure, but I thought I heard some of the grade 5/6 students commenting about how cute Marianna was followed by "... it's too bad she has a brain tumour". For me, this prompted a need to educate the school yard. I asked the principal if I could talk for 5 minutes at the next school assembly (which is every Friday at 2:30pm, where all the kids, teachers and various parents are in attendance). What follows is the lecture that served the purpose to educate the school.

Being generally overextended with duties from my own job, I asked the principal if, perhaps, some of the kids, say the grade 5/6 class, could print some pictures of chromosomes for me, that I could use as visual aids during my little presentation. In the little back and forth we had where the principal indicated that my request to have the students get pictures of chromosomes wasn't realistic, that I was welcome to talk at assembly but I should get the visual aids myself, I became pretty certain that she wasn't very sure what chromosomes are.

Carlton Gardens Primary School 27 March 2009:

I have two jobs, I'm Marianna's father and I'm a professor at Melbourne Uni. That means that people ask us questions and I try to figure out the answers and teach everyone what the answers are. I've heard some bits of conversations at the playground wondering whether Marianna is different and I asked Tina if I could tell you what I know about the answer to that question.

The short answer is that Marianna has no medical problems and she really likes red. The long answer is very interesting.

Just like this school is made of lots and lots of bricks, our bodies are made of lots and lots of cells. They are really tiny. If you take one of your cells and look at it under a great big microscope you'll see very tiny little wormlike things in it which biologists call chromosomes. Essentially these are big books that contain all the information about how your cells and your body is put together. We only understand a few things about these books.

These books are written in a code that uses only 4 letters, ACTG, and we don't understand how to read this code. We know that these books must say things about how to put together cells to make really curly hair like Lola's, and how to put cells together to make pretty brown eyes like Marianna's but we don't know how to read these books cuz they're so tiny, they're written in code and they contain so much information.

If a person has one of these books Y then that person is a boy. If a person has two X books then that person is a girl. Marianna has 2 X books. We can't see very well, but we've looked at some of Marianna's cells and we think that she has 3 of these 21 books. About 1 person out of every 700 has 3 books 21. We don't know what Marianna's extra book has in it.

I have a few guesses: It has something about how her muscles are made that makes her very flexible and makes her feel like she's losing her balance often. You notice this when she talks on the foot phone and when she has to think really hard when she goes upstairs, or when she has to think hard about how to move the muscles in her hand when she draws a cat.

Her extra book has something in it that makes it very easy for her to read, to understand everything she hears around her, and to memorize words of songs and melodies.

Her extra book has some information so that her tongue is built pretty wide, which makes her have to think hard in order to talk. It's like when you try to say supercalifragilisticexpialodocious (or try to spell it). That's why sometimes, for Marianna, it's just too much effort to talk and it's better for her at some moments not to respond.

Also, her extra book has something in it that makes her really like red.

But mostly we have no idea what our little books say. Maybe you all can be professors and help me figure out the answers and teach them to me.