

Reflections on a Personal Interview

“But [knowing I’d lose my sight] wasn’t a scary thing because I’d seen other blind kids, and so, okay, that’s just my path... so I just got on with life.” (RM, personal communication, March 9, 2013)

This statement from my informant, a 47 year-old woman, summarises the critical factors which allowed her to manage her vision loss. She “just got on with life” because she had connections to capable blind people who provided support, acceptance, knowledge and skills; the determination to live an independent, full life; and the ability to confidently accept her vision loss, all elements she advised teachers and families to develop in their children with vision impairment (VI).

RM, her mother and a sister all have aniridia, a genetic eye disorder characterized by a complete or partial absence of the iris, which along with other associated eye problems resulted in low vision and progressive, total loss between birth and 25 years old (Genetics Home Reference, 2013).

Childhood: Acceptance, Support and Preparation

Since VI was the norm in RM’s childhood home, she learnt to perform activities of daily living with little or no reliance on her vision- “Mum taught me to do things as a VI person... She was just logical in the way she did things... she accommodated my needs but I was expected to do my share.” Though her mother was the first in her family with VI, her vision wasn’t poor enough to qualify for specialist teaching, so she “just made do”, devising her own strategies. Normal expectations, problem-solving skills and determination to be independent were imprinted on RM, who emphasised the importance of teachers and parents of children with VI reinforcing these attitudes.

As RM’s father was Sri Lankan, the children were teased for their darker skin, so were taught to “stick up for ourselves... Dad had a strong sense of justice and fairness”. This served RM well: “Mum was really supportive with self-advocacy... I had to speak up for myself... like ask the bus number when a driver told me to read them and I had to say I couldn’t. Yes, I had some low self-esteem due to my disability, but I still knew [being bullied] wasn’t right.” She considers assertiveness one of her most important attributes.

Her family’s acceptance was crucial to her confidence as a person with VI: “I had a really supportive mum... she never tried to hide my blindness, never mollycoddled me, and I see kids who are mollycoddled now.” Surgery that might have reversed her vision loss, or caused total blindness was declined because, “Mum decided she couldn’t explain to a four-

year-old why she'd suddenly lost her sight". Though her mother "always agonised" over their decision, RM supported it: "I was happy to live with [VI]... [Mum taught us] that attitudes were more important than blindness. Mum never spoke around me about how sad it was that I was going to go blind- I see so many parents doing that when their child is right there- what's the child supposed to think [about having VI] when their mum thinks it's terrible?"

RM always knew that she had VI- "One of the benefits was that Mum was always very open with me", learning at 8 years-old that she would go totally blind by 28, "[which] wasn't a surprise since I was forever going to ophthalmologists." Each loss "was a little bit distressing... but I always identified as a VI person and... knew I'd go blind." At 25, surgery to save her remaining vision failed. She remembers thinking, "Well I feel miserable but hey, I know other blind people who coped just fine."

Her childhood acceptance of vision loss meant she was emotionally and strategically prepared, and the support, independence and skill learning provided by learning with others with VI was critical: "Being a fairly good 'partially' and using braille [at the Partially Sighted Unit (PSU)] gave me the benefit of seeing other 'blindies' - and I call them 'blindies' because that's a term I can own as a member of the blindness community... I got to see lots of strategies, like using your finger over a cup to pour, or [echolocation]... so I felt confident to use them later... I really treasured that 'special school experience'; apart from having access to all that [VI-specific] information, I learnt braille everyday whereas nowadays kids are so dependent on their aides... In my twenties, I was really very anti-special/blind schools... But now as I'm older I see the benefit of peer support, and having some things that are just blindness-only, but it needs to be a balance of integration as well." She attended PSUs for mainstream junior primary, a blind school for late primary and another PSU in year 7, but "coped enough" to be fully integrated from years 8-12.

Young Adulthood: Advocacy and Education

School wasn't perfect- she wasn't accepted into her desired university courses due to poor scores largely resulting from a lack of timely braille material and lowered expectations. At her blind school, all students learned at the slowest student's rate, which she found frustrating. When she was mainstreamed in high school, she advocated for the PSU students there who weren't being taught at the level of their sighted peers to the principal. The head of the PSU was notified, and "tore strips off me... I learnt it's important to know the systems that are in place, how to be assertive in a good way". She had difficulty socialising in high school- locating friends outside class was hard and she needed time to organise her books and brailled for her next class- so she made friends with other blind students with the same issues. She experienced bullying as did the other blind students, though she asserted herself and reported it.

She met her partner J at 22. He and their families convinced her to attend university after believing the work would be too hard due to her high school experiences. She ended up completing an honours year “for that extra bit, because I was competing against sighted people- that kind of planning is very useful”. She believes, “A good education is number one- a tertiary one is essential, it comes with opportunities for integration, employment, confidence- you read more books, become worldlier.”

Adulthood: Strategies, Humour and Guide Dogs

Regarding the impact of her VI on her professional and public life, “[I am] an ambassador every time I step outside... you’re going to talk to people more, so you’d better be good at it. I try to make people comfortable with humour.” She employs a range of strategies at work and in public, including listening carefully to passers-by to determine who to ask for assistance, knowing what information she needs to request and using a range of technology. She and her blind friends occasionally share strategies and systems they employ to stay independent.

When asked how they’ve managed her VI's impact on their relationship, J laughed, “It’s meant I’ve lived with a lot of [guide dogs]!” RM stated, “There is compromise... our activities are modified... but still quite a good quality... [when we travel] we plan itineraries we can both do... We talk about how we’ll manage something... and we have our own activities... I guess I am dependent on him in some ways- he’s my dressing mirror- and as we’ve grown together I’ve learnt to ask for what I need. We’ve worked out our own strategies... he’ll say ‘hands in’ if I’m leaning on the table and the food’s arrived.”

Insights: Blindness skills and "COPE"

She advised, “Special schools need to teach at [mainstream curriculum] level- there’s so much more integration now but not enough time [to learn blindness skills]. Parents need support to teach these skills. Kids [with VI] need exposure and opportunity, and to be allowed to fail- it’s not that they failed but got up. They need input into their program... ask how they feel when assigned to run with someone in PE they dislike. Give them networks. Role models are very important, but so are inner abilities.” She devised an acronym, ‘COPE’, “which stands for Confidence- to ask questions, that it’s okay to feel around; Orientation- to the environment, to systems; Peer Support, where you can go to be around other VIs, get tips- but we can’t live there because it’s insulated; and Expectations- make them high but explain why and give them support to reach them.”

My Reflections

RM's story, advice and insights reinforced many of my beliefs about good practice for teaching children with VI. I found her story an example of the power of encouraging and teaching confidence, VI-specific skills, problem-solving skills and assertiveness, and having connections to the blind community. A range of respected sources reference these as critical for educators and families to develop independence and employability (American Federation of the Blind, 2013; Holbrook, 2006; Wolffe, 1999).

I would like to create more opportunities for student input by developing learning goals together and seeking feedback, and improve problem-solving skills by teaching thinking skills and offering open-ended questions. I need to offer increased support to families to teach life skills through information afternoons or home visits. Other priorities include teaching my students to accept their VI through role-modelling and using RM's strategies for navigating, socialising and daily living.

Academic success is only part of a full life, and I want my students to find success in their private and professional lives like RM has. Her life is full indeed- of travel, friends, wide-ranging interests, fulfilling work, a healthy relationship. I am fortunate in my work to use her as a role model for my students, who would be wise to follow her example and grow up to be the sort of person she has become.

References

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