Meryl Alper says the relationship between disabled children and the digital future is a complicated one. In this post, she looks at one U.S.-American family’s story and discusses how it’s characteristic of many parent’s talk of the future, digital media and its role in their disabled child’s paths and plans. She is a PhD candidate at the Annenberg School for Communication and Journalism at the University of Southern California, and author of Digital youth with disabilities. Meryl’s work focuses on the social and cultural implications of communication technologies, with a focus on disability and digital media, children and families’ media use and mobile communication.

The new media landscape for young people with disabilities is undergoing a significant technological and cultural shift.¹ With a Special Education section in the Apple App Store and autism-friendly film screenings and Broadway shows, never has more attention been paid to disabled young people as a commercial audience.

How are their parents making sense of such media and technology? I explored this question in Home screen home: How parents of children with disabilities navigate family media use.

Among the parents I talked to, I heard a great deal of what I refer to as ‘future talk’. While talking about the future is something that nearly all parents do, these conversations were characterised by three main themes:

- preparing for the uncertain path of their child's individual growth
- developing contingency plans in light of a society largely unprepared for the needs of their child as an adult
- inevitability of technological advancement and its impact on their child's life.

By focusing on one family’s story here, there are some surprising ways in which media becomes an integral part of this ‘future talk’, revealing something about parenting for a digital future.

**Preparation**

Vanessa and her 10-year-old daughter Moira² are white, US-born citizens who live in California. Vanessa does not have a college degree or a full-time job. Moira is on the autism spectrum. She has significant difficulty speaking and uses an assistive speech app called Proloquo2Go on the iPad to aid her communication.

During my interview with Vanessa, we discussed Moira’s evolving media preferences. Much to Vanessa’s bemusement, she mentioned that she had recently discovered that Moira liked country music. “I’m playing all this rock for her, because that’s what I like,” Vanessa said. “But she’s her own person. If [Moira] likes country music, then I need to expose her to that. We’ll see. Who knows, she may be a country girl.”

While Vanessa supported Moira developing an independent musical identity, she expressed reservations concerning her pre-teen daughter’s younger-skewing tastes, particularly her liking for YouTube videos of The Wiggles, a musical pre-school TV series. “I just don't want her being 20 years old watching Wiggles. She can, but I think I’d have to restrict the time,” Vanessa said.
For Vanessa, parenting for Moira’s digital future includes ensuring that Moira’s media interests remain ‘age-appropriate’. And like other parents of children with a disability I spoke with, she anticipates that mediating her child’s internet use will extend far beyond adolescence.

Credit: T. Lawson, CC BY 2.0

Contingency

“It’s a bigger question,” I asked Vanessa, “but do you think much about [Moira] 5 years from now, 10 years from now?”

“That’s all I think about,” she replied matter-of-factly. “Everything I do with her, every interaction, everything I want to teach her is always with her later years in mind. I have to try to teach her to be as independent as she can possibly be.” Parenting for Moira’s digital future was inseparable from Vanessa’s heightened concerns about her daughter’s future wellbeing.

This sense of responsibility weighed heavily on Vanessa – not only was she preparing for Moira’s digital future, she was also preparing Moira for a world ill-prepared to accommodate her independent living as an autistic adult. While more privileged parents might be more able to mobilise economic, social and cultural resources to navigate the Byzantine complexity of special education systems, insurance policies and assistive technologies, much of this was a struggle for Vanessa.

Inevitability

Parental future talk also concerned the hope that technology would progress in the coming years and improve the life of their child. Vanessa wished there were “some sort of app that could give a person with autism prompts [...] if they’re out in the community,” such as traffic safety alerts. “Thankfully we live in this time of technology that’s going to facilitate that. That’s already facilitating that,” Vanessa remarked.

Vanessa was far less confident that social services for autistic individuals would improve within the same time frame. She spoke of her frustration with their local police department, which did not have adequate training for how to work with autistic individuals who communicate through electronic speech aids. She also expressed anger at her local school district for violating Moira’s educational right to assistive technology on multiple occasions. Some futures seem more inevitable than others to parents of young people with disabilities.
Preparing for the unpredictability of their child’s development, coming up with contingency plans for their child’s transition into adulthood, and avoiding technology that could aid these plans all shape how parents of disabled young people conceive of a digital future. Vanessa and Moira’s story raises a number of questions about what it means to raise children with a disability in the digital age:

- How might we, as a society, build digital and social spaces where families of young people with disabilities – across class, racial, ethnic and linguistic backgrounds – can feel welcome, safe and supported?
- What services and policy changes are needed so that these digital and social spaces can serve families in the most effective ways?
- Do existing theories of parental mediation adequately explain the role of media and technology in the lives of disabled children and their families, especially as these children transition into adulthood?
- What might parents of non-disabled children learn from how parents of disabled children develop strategies for navigating family media use?

The relationship between disabled children and the digital future is a complicated one, as evidenced by their parents’ ‘future talk’. As critical disability studies scholar Alison Kafer notes, the future is often popularly imagined as a time in which disability either does not exist, or it is assumed that a future lived with disability is no future at all. Kafer calls on readers to imagine disability as an asset to our collective futures. In turn, digital producers, policy-makers and researchers must account for a digital future built for and by young people and adults with disabilities.

NOTES

² See Alper, 2014; Pitaru, 2008; Söderström, 2009; Tsaliki and Kontogianni, 2014.

¹ Names have been changed to protect the identity of individuals.