

Beyond BLONDE

The Albinism Fellowship Of Australia Newsletter



**Benj and his collection for the
Tanzania Charity Drive**

Editor: Elizabeth Beales
Design: Annette Ferguson
Assistance: Shari Parker
& Helene Johanson

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Mashawna Thompson is a “mom” of three from the USA. Her youngest child, Lyra, has albinism. Mashawna is a true advocate for children with albinism; her enthusiasm, dedication and quest for more information is admirable. Mashawna is on the board of directors of NOAH (National Organisation of Albinism and Hypopigmentation)

Here, Mashawna shares with us of her experiences with Lyra.

Beginning this year, her first year of preschool, Lyra has been learning both print and braille. This concept is known as “dual-media.” I must admit, when Lyra was a baby, and we were still coming to terms with her condition, the LAST thing I wanted to hear was someone telling me that Lyra might need braille. Braille was for blind people and my baby was NOT going to be blind.

Most of what I heard and read up to this point told me



Mashawna Thompson

that Lyra's vision would be good enough that she could read print and not need to learn braille. So how did I become such a strong supporter of dual-media?

The concept was first introduced by one of Lyra's Teachers of the Visually Impaired, when she was receiving early intervention services. At this point I began doing my own research. I not only read dozens of articles and papers, I also talked to other parents of children with albinism and adults with albinism. I was beginning to realize that there was just not enough evidence to prove to me that Lyra would never need braille. I became convinced that for some situations, at various times in the future, braille might be her best option.

I learned that the use of braille may prevent or reduce eye strain, headaches, and neck and back problems caused by poor posture. With braille, Lyra would not be dependent on certain

lighting conditions, print size, or the availability of magnification devices. If she has trouble reading her own handwriting, braille could be used for taking notes.

"I dream of being able to read a book myself, not through an audio book, and be able to read and read until I feel like stopping – not because I'm getting a headache or am tired of holding a magnifier or sitting in some strange position – but because I just want to stop," (Heather Kirkwood, adult with albinism.)

It's true, the majority of people with albinism do not read braille. Why is that? It may be that they truly don't need it. It could be that they were never given the opportunity to learn braille.

"I would have benefited greatly from learning braille as a young kid, but indeed wasn't even

offered the opportunity until adulthood – an area where I feel the system let me down.” (Heather Kirkwood, adult with albinism)

Just because that is the way it has always been done, doesn't mean it has always been the right decision.

“In the past, teachers struggled over the decision to teach braille to students who had the capacity to use print. However, students who were inefficient in print reading and writing had no alternative other than to struggle with that inefficiency.” (Koenig and Holbrook, 2000, p. 296)

There are some adults with albinism who have said that they learned Braille, but don't use it. When I hear this, I immediately want to dig deeper. In order to understand why they learned Braille, but don't use it, I find it helpful to ask them a

few more questions. What age did they begin learning Braille? How long did they receive Braille instruction? Did they learn Grade 1 and/or Grade 2 braille? Did they learn to read braille tactually?

The answers to those questions make a big difference in whether a person who learned Braille will actually be able to use it effectively.

I know there are many examples of people with albinism who excelled through school and went on to become very successful adults in lots of different career areas, but at what costs?

Marleena Coulston, adult with albinism, was introduced to braille in 7th grade, after her reading speed had begun to decline, but at that point, she says she was very resistant to it.

“I most definitely have had to work harder than

my peers, due to my eyes tiring from the heavy amounts of reading. Everything took twice as long for me to complete and do. Tests always took longer, my homework always took longer...I think that braille would have made a difference. I think it's a good thing. I probably would have adjusted better if they had introduced braille to me at an earlier age."



Lyra Thompson

The purpose of her learning braille isn't so she can get away with doing less. I want to enable Lyra to do more than just get by. I want her to have the confidence and ability to reach her highest potential. Her ability to succeed should not be limited by her visual impairment.

I do want her to learn the value of hard work and even struggle at times, not because of her vision, but because she is continually provided a challenging curriculum.

She needs to acquire the skills

necessary to survive in the real world. She needs to know that she can't truly become successful by constantly using her visual impairment as a crutch. I've stopped lowering my expectations and no longer

Past examples and trends do not prove that my child won't need it. The ranges of visual acuities in people with albinism vary widely. No one can predict, with absolute certainty, whether or not Braille will be useful to Lyra in the future.

focus on her limitations. I don't make excuses for her; I let her try something again and again.

"The pupil who is never required to do what he cannot do, never does what he can do."

~John Stuart Mill.

This decision we've made for Lyra has not been without criticism. Here are some of the arguments we've heard.

**I'm trying to make her blind.*

I know that Lyra is not totally blind, which is why I don't expect her to learn and rely on only braille. However, she is not totally sighted either, so why should she be expected to learn/rely on only print?

One of the reasons we were told, against her learning braille, was that

**she is primarily a "visual learner."*

We agree that Lyra is visual

learner and want to optimize this strength when it's most effective. However, it doesn't mean that her vision will always be the most efficient way to access information. If relying on only her visual ability for reading causes her to fall behind her peers and often results in physical pain, why would she even want to read.

"The only books I have read for pleasure are books that I am EXTREMELY interested in reading. Had I learned braille I might have had more of a love for reading. I just looked at reading as a BIG CHORE." (Margaret Mary Campbell, adult with albinism)

**Using braille will make her look blinder.*

In my opinion, holding a book/paper an inch away from her face or sticking her nose down to her plate of food would be much more noticeable and make

her appear "blind." Using braille will not make her look different, any more than wearing head phones for audio materials, using a CCTV, or using a hand held magnification device would. Children will always notice differences, it doesn't matter what the specific difference is.

Our approach on dealing with this is basically just being aware and looking out for any social or emotional issues.

**She will just read the dots visually or will be resistant to learning braille.*

Children will often look for the easy way out; it doesn't mean we make learning something optional. If she's trying to read the dots visually, there are lots of things we could try to help her break the habit... put a piece of paper over her hand or place a partition of some sort between her eyes and her hands. One easier

and maybe even more effect solution could be for the teacher to require the student to maintain correct posture when reading braille. If a child is sitting up straight, not hunching over or bringing the paper up close, it is unlikely that he/she would be able to read the braille dots visually. Learning braille is only as hard as the teacher makes it. If the teacher goes into it with the attitude and belief that kids with low vision CAN'T learn braille, it will affect that student's confidence and ultimately his/her success in learning braille.

**It's unnecessary to learn braille, with today's technology. Why bother when there are so many other options.*

There are lots of alternatives to braille available, low tech and high tech magnification devices, audio books, large print, and more, but there are limitations with all of them.

Other than audio format, all of the other options are visual so there is still the issue of eye strain and fatigue. Of all of the available options, none of them are as versatile as braille. You can read braille in bright light, low light or even no light. Braille doesn't require a computer, an audio player, or even electricity. You can't assume that what works for one person will work for everyone.

"I had a tough time adjusting to books on tape because my mind wandered. I'm actually, IRONICALLY, a "visual learner."

(Marleena Coulston, adult with albinism)

Chantel Alberhasky, parent of a child with albinism said,

"It was once believed that technology would replace braille for people with low vision, but just as technology cannot replace print it cannot replace braille."

Technology has had a huge impact on the use of braille, not by replacing it, but by making it even more accessible/attainable. Through the power of technology and programs like Book Share and Web-Braille, books in digital format can be downloaded from the internet and printed on an embosser for immediate access.

* It should be her choice.

Yes and no. Lyra is not yet old enough to understand the importance of becoming a good reader. Even if when she is a little older, she becomes resistant to learning braille, I will still require her to continue her braille instruction. I'm sure many students have complained about learning how to read print, but we would never let them opt out of print reading simply because they didn't like it. Yes, when Lyra is an adult, I want her to be able choose if, when, and where she wants to use braille. In order for

her to truly have that choice, and really be equipped to use braille, she must be proficient and fluent with it. Of course she won't think it's useful, or recognize the possibilities with braille if all she ever learns is the braille alphabet.

"My son is only finishing kindergarten, but he is learning braille along with print. I am just giving him the tools to help him be as successful as he can be," said Chris Kramer, parent of a child with albinism.

Braille is a tool, just like a Closed-Circuit Television (CCTV) is a tool. Neither can be used effectively without proper training. With both tools, it is necessary to provide the child with the knowledge and skills required to benefit from its use. You must begin that instruction very early, before it's even needed.

When that child is older, he/she may or may not choose

to use a CCTV or braille, but at least he/she has the knowledge and skills needed to really make that decision.

**I'm causing her to be less independent or making her more "disabled".*

According to Merriam-Webster, the definition of disable is to make incapable or ineffective; especially: to deprive of physical, moral, or intellectual strength. In no way am I trying to make her less capable or weaken her ability to succeed. I'm doing the exact opposite. I don't want to limit her, I want to empower her.

"Don't lower your expectations to meet your performance. Raise your level of performance to meet your expectations. Expect the best of yourself, and then do what is necessary to make it a reality" Ralph Marston.

I've heard too many examples of adults with

albinism not being able to read for long periods of time and having slower reading speeds and suffering from intense eye strain and headaches. I can't say for sure that when she is older, she will definitely experience eye strain and headaches, but I can't say for sure that she won't either.

"As a 35 year old I personally wish I had learned braille, especially with some of the things I've done in the workplace. I've had to give several lengthy presentations, too long to not have notes for... and it is not good PR to be constantly peering at a paper less than an inch from your face rather than looking at your audience," Julie Stevenson, adult with albinism.

The decision of whether or not a child should learn braille should be based on input from his/her IEP team. It is not a decision that should

be determined based on the opinion or recommendation of just one person, including a doctor. Information from medical professionals is very important and very useful and absolutely must be considered in the development of the child's IEP. However, the decision to provide braille instruction is an educational decision, not a medical decision. Would an education professional be qualified to make a medical decision? No. So why would a medical professional be qualified to make an educational decision? When making that decision, the team must consider the child's current needs and also his/her future needs.

The reading requirements of a 1st grader are different in many ways than the reading requirements of a high schooler. As the print size gets smaller and reading requirements increase in amount and complexity, will the student still be able to keep up?

Parents considering braille

should request that their child receive a quality learning media assessment that evaluates their child's abilities, not just in 1 controlled environment, but in a variety of settings. However, that alone cannot be the only determining factor. One of the provisions of IDEA is that a school may not use any single measure or assessment as the sole criterion for determining an appropriate educational program for the child. More information about the IDEA provisions regarding braille instruction can be found at the following website. <http://idea.ed.gov/>

As of now, in terms of her cognitive abilities, Lyra is doing extremely well. She is very imaginative and highly curious. I expect her to excel in school. Why shouldn't I? What if in our family, we expect more than just average academic performance? What good does it do a child to base goals on ideas such as "at grade level" and "proficiency",

if he/she is capable of excelling far beyond those standards? Someday Lyra may decide she wants to be a brain surgeon, or a chemical engineer, or who knows what else. I want her to be equipped with any tools/skills she might need along the way in order to accomplish that kind of success. I want to increase her independence and give her more flexibility. Whatever she decides for her future, I will do everything I can to help make that possible.

The bottom line is Lyra is an individual. My husband and I are her parents and we are making this decision for Lyra. It would be unfair to say that what goes for one person with albinism, goes for all. I won't criticize parents who choose for their child not to use braille nor will I criticize adults with albinism who don't use braille. That's their decision.

Please respect and understand that based on

the needs of our child, we are making the best decision possible for our daughter.

"Don't limit a child to your own learning, for he was born in another time"
~*Rabbinical Saying*

References

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Merriam-Webster. (2009). Disable. Retrieved August 4, 2009, from <http://www.merriamwebster.com/dictionary/disable>. career areas, but at what costs?



Lyra Thompson

Mashawna keeps a "blog" of her life with Lyra at www.parentofachildwithalbinism.com. You'll also find links for useful information regarding toys, books and so forth for your own child.