

Designer babies vs. Designing your baby: Can personal genomics harm your children?

What if a test could predict if your baby was destined to be a science wiz or a history buff? A writer or a mathematician? Would you do it? Would the results change how you raise your child? Instead of opening them up to a wealth of possibilities during their youth, would—or should—you narrow your child's activities based on their test results?

Scientists in the United Kingdom are exploring those very questions.

Based on their research, the scientists say that a child's subject choice (i.e. humanities vs biology) as well as their success in the subject is largely due to their genetics—up to 80 percent in some cases.

“We are really arguing that individuals can actively choose and create their own educational experiences partly based on their genetic propensities,” Kaili Rimfeld of King's College, London explained to [the Guardian](#).

And this is not the only genetic information now available to new parents that purports to offer an insight into your child's future strengths, skills and interests—and their deficits. All of which a parent could use to raise their child. Depending on the results of these tests, there are a number of scenarios that could play out:

If your child has genes that predispose it to being an athlete, have her or him play as many sports as possible. If your child tests as having a learning disability, get them help as young as possible. If your child has a predisposition for allergies, no PB&Js. Musical genes? Buy them a piano.

We aren't yet at a point where parents can select the genetic traits they want to be passed along to their children—[designer babies](#). But with our quickly expanding understanding of genes, parents can now access (albeit often at great expense) genetic data to *design their baby's* life by customizing their child's experiences, using the personal genome as a guide-book on how to raise her or him.

Designing your baby is a growing trend fueled by studies (like the one cited above), the wide availability of at-home genetic tests, and the infatuation millennials (who are just starting to become parents) have with [personalized genomic data](#). At face value, understanding your child's personal gene map may seem like being a good parent; after all, it could theoretically help you raise your children to fulfill all of their potential. On the other hand, such information, if used improperly or misunderstood, could end up damaging children—and if used widely it could hold back an entire generation.

Is knowing half the battle?

When it comes to knowing your child's genome, a line in the sand needs to be drawn. It is in a parent's—and their children's—best interest to know if their genome poses any of the 'have it, you got it' medical conditions. These are genetic diseases like sickle cell anemia and cystic fibrosis in which a well understood and characterized mutation is likely to lead to a specific, serious disease. There's ambiguity with these conditions; if a genetic test comes back positive, your child is very likely to end up with these

condition (there are sometimes mediating gene-gene and gene-environmental influences). These are often called Mendelian diseases as the conditions are linked to one testable mutation. To this end, most states have lists of recommended disease conditions that every child should be tested for at birth. And there are numerous testing companies, such as [Counsyl](#), that offer these services, and insurance companies often cover them.

But on the other side of that line are genetic predispositions—both for traits and diseases. These conditions are often multi-factorial rather than Mendelian; scientists do not yet know what combination of genes or genetic and environmental factors, are likely to lead to these medical conditions actually showing up. Tests offered by 23andMe, Genomic Express and DNAfit, among others, make finding out that one might possibly have or evince a genetic disorder as easy as spitting into a tube or swabbing a cheek.

In some cases knowing what predispositions your child may have might improve their life. Autism spectrum disorder (ASD), which has strong genetic as well as environmental etiologies, falls into this category. The test costs parents [from \\$1,000-\\$5,000](#), but they provide some genuinely actionable information. As almost every expert on the condition will tell you, children who have ASD should get professional help early—and the earlier the better. Unfortunately, [not every parent](#) is an expert on what symptoms are indicative of autism. And even if they are aware, denial is common; *their little angel can't have autism*. Some parents worry their child may get labeled as underperforming at an early and formative age, and that stigma will stick with them even if they outgrow certain behaviors. These and other reasons lead parents to stall getting their child diagnosed. But knowing a child has a genetic predisposition for autism could serve as a wake-up call for a lot of parents.

And it's not just autism that falls into a 'test might help inform us' category; anxiety and learning disabilities have genetic roots and can be alleviated to some degree by early intervention. A similar case can be made for non-neurological conditions. [Some patient surveys](#) suggest that providing them with data about their personal genetics leads them to make better decisions about their health. So if a parent knows their child has a variant linked to high blood pressure, they can make sure the child is on a diet that will accommodate that predisposition. Or if a child's genes suggest she may be prone to a prolonged recovery from an injury, a parent can choose to keep their child out of sports or direct them towards minimal contact ones.

On the same grounds, if a child has the genetic profile of an elite athlete or musician, wouldn't you be remiss as a parent to if you did not at least give him the opportunity to exploit his natural gifts?

When can this information be dangerous?

Knowledge can cut both ways; studies have shown that forcing your child into activities can be detrimental to her development. And many people develop skills through hard work, often surpassing the accomplishments of the more naturally gifted. Learning is complex. So many traits are multi-factorial with genetics tipping the needle slightly, and other factors like environment and culture play significant roles in a feedback loop. Luck matters as well. Your child's genetic predispositions don't define him, they just help describe him. Pigeonholing children because of controversial and often misunderstood genetic data that suggests they are not musically or athletically inclined can't be good for their development.

It can't be stressed enough that there are only a limited number of genetic conditions or predispositions that tests now available can identify. Despite the widespread and ready availability of these tests, many of them provide data that most scientists find 'sketchy' or even deceptive. For example, the firm Simplified Genetics offers a test that it claims can gauge your child's susceptibility to concussions based on a single gene variant—but that variant is only loosely linked to concussion risk. There are likely dozens or even hundreds of other genes that could predispose or even help protect a child from being concussed. And that does not even take into account environmental factors. Guidance based on one allele ranges from useless to dangerously deceptive. Any parent who makes decisions such as whether to participate in a high contact sport like football based on this kind of pseudo-science risks denying their children the opportunity and benefits of safe athletic competition or might give them false confidence that their child is bullet-proof on the gridiron. (There is a lively debate over the science on the gene variant Simplified Genetics tests for; [I analyzed this in more detail here](#)).

There are limits to what we can learn from these tests even when they might provide some useful information. Consider again ASD. There are substantial benefits to knowing if your children has an autism gene. But those tests, which can be expensive if not covered by insurance, can only explain autism susceptibility in 16 percent of cases. That's because there are dozens of genes linked to this disorder—and available tests only evaluate a few of the known ones. A false positive diagnosis—which is quite conceivable because of the uncertain nature of these tests—can be as harmful to your child as a missed diagnosis. Enrico Gnoulati a clinical psychologist has [addressed](#) how giving your child a false ASD label in youth can have ramifications down the line if it's wrong:

[T]here are lots of problems that parents may not appreciate. There are many occupations where having a history of mental illness can foreclose a professional opportunity: positions in the military, police force, high-security positions...Disability and life insurance rates may be higher for you. Being mislabeled can also create a self-fulfilling prophecy: insofar as parents or children reify the diagnosis and believe something is due to a disordered or fractured brain, they may assume those children have no control over their behavior. If they have a broken brain, we automatically assume we shouldn't hold them responsible for their behavior. So then they may not be motivated to change and may fall back on brain-based rationalizations for their behavior.

Parenting is hard. You can never quite escape the feeling that you are not leveraging their undiscovered qualities. That's why designing your baby's life based on their genetic profile is such a seductive option.

But caution is advised. The order of the A,C,G and Ts in you children's genome is just one aspect of who they are and who they will or could become. Focusing on those letters may do more harm than good.

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