

12/28/89,

DR. Paul Billings <sup>genetic underclass</sup>

don't use exact #s of people.

Say,

I've had about 60 responses

Something about it in NYT

magazine last weekend,

"nearly 60 people responded."

About 1/2 met the criteria for  
inclusion

They had to show by the story,  
or supporting doc, or collabor

A lot of people who are disabled  
are unhappy about the disabled  
& think about it & get frustrated  
in our society.

They have to make hold

Joss

What I was trying to look  
was people w/ genetic disas,  
~~that~~ that were sub-clinical  
, minors, or asymptomatic.

Sub-clinical: something that  
is detectable but not  
really producing signs

A list of genetic malformations  
that make your fingers crooked

Ex from study:

minor --  
A couple of letters  
@ charcot-marie-tooth.

neuromuscular disorders,  
very genetic + clinically  
heterogeneous.

H genetic. SoB dom +  
typ rec.

A whole range - weakness of  
the lower extremities to  
severe.

wasting of muscles  
in hands + legs.  
you loose lots of strength

The people who work in bed  
very, very much must.

They dragged their feet  
a little bit.  
yet they were treated  
as if they had a sig. disab

Many had trouble getting  
any increase at all,

one the children had gotten  
a job, had reported fire  
disability, + had not gotten  
the job as a result  
phot co

A person in a sales job  
had been driving for  
20 yrs w/ this disease.  
No accidents, his phys had  
eval.

But when his insurance  
co found out that he  
had this condition. They  
cancelled his auto insurance.

how? That's a good question.  
It's very unfair to us.

I don't know.

If you apply for extra coverage -  
mortgage, excess.

In any of those cases  
what you have to find -  
people who offer truthful  
→ admit what going  
on

phys - to bill for services -

If someone comes in +  
visiting is wrong - you don't  
get paid.

↓ NO good evidence

That the annual physic  
should be age 50 &  
much less is  
medical practice.

Children - immunize make  
sense. Learning + vision.

Doctors, in order to get paid,  
are being asked more + more  
to list a diagnosable condition  
in their chart.

If I think spending on health  
will cost me \$100.

If I put down - hypertension as  
a diag - and some other  
disorder which we talked about -  
then much more likely to  
get my \$120.

Family history + any kind of  
odd findings, instead of  
putting down Dues, Ray would  
put down C to facilitate  
the billing process.

The break in accountability is  
a natural consequence of  
the way in which the public  
billing of physicians is  
structured in this country.

had gestational diabetes?

woman who had a child w/ CF  
and became preg again. They  
the wife of that preg was screened  
for another child w/ CF

Re HMO that was holding  
her health coverage

5 year old w/ CF  
second preg w/ CF  
They decided not to term but to  
cure.

If looks tame - for most  
conditions where there is reversible  
clinical course.

(30-50% of life w/ CF)

sig # of people given better  
feels & etc.

as more + more people discuss their  
new children

~~confidential:~~ Because Ray had a 5 yo  
that they obviously loved, they  
decided that they were not  
interested in adopting.

The family decided not to adopt.  
The HMO said we are going to limit  
the count of 1 for the care of  
this child as well as the other  
child - a sig limitation.  
(being irresponsible)

They contested this, they hired a  
lawyer + threatened to sue -  
settled out of court -  
I'm not sure.

TWO CF IDENTIFIED

There were two exactly  
identical cases, one from  
the south, one from NW.  
~~—~~ absolutely identical.

heard about this from genetic  
counselors.

In this country in every state,  
Screened for biochemical  
disorders. Please -

The most astonishing is that  
② some pent insures do say  
we are not going to pay for  
The treatment or plan after  
some pent.

July 89

EDS - some people/  
very mild disorder.

Type I,

Five- $\rightarrow$  to a conference

in Virginia  
NTL EDS  
+ confid.  
~~acceptat~~

gave a talk in a room from

Texas - she said the people

so simply said we're not  
going to cover this any more,  
even though there was ~~no~~  
further.

PKU - Both genetic counselors +  
patients have told me that  
INS cos say @ see part  
they are not going to pay for  
people that consent to PKU  
screening.

These problems are finished  
on you ~~WIC~~ you take!

Yesterday, it is better to  
FD These people than  
have them be restarted.

The diet costs \$4000 a year.  
<sup>added</sup>

for special law physicians can  
they will be excluded  
if they try to get covered  
(change laws)

The implication is people are  
obliged to change jobs, ~~X~~  
speak up @ work.  
esp. @ small size.

A lot of us look around.

The idea that Pay or ID to  
employers @ all and some  
part of the bottom line is  
ridiculous.

It is ~~advice~~ that you  
employee should take into  
~~account~~ an illness to your  
child.

People @ risk for Huntington's  
disease:  
1. mother or father.  
and 2. identical cases

~~Both~~ Both women in 30s  
had both applied for adoptions.  
Both from midwest.

~~The way we figure risks - if your~~  
~~parent is affected, you have 1:2.~~  
as soon as you show signs, 1:1.  
The more info, the less.

most common for fashion is 30-40

Adopt - The street was outta the try  
to have a child + go through  
penatal care + ~~the~~ adoption -  
she went for adopt.

Both started for adopt -

Ray both freely admitted when

The adopt agency said they  
wouldn't allow them to adopt  
because Ray wouldn't be sure  
that in 15 or 20 years the  
mother would be well.

\* ~~space~~

I think... That everybody is  
at risk. In sex families

The risk for sex things is known  
or it is more quantifiable.

But I don't think there's

No change...

Illness - as much as it is  
a difficult situation it can  
be a learning op.

families together as  
a criteria for adoption.  
As a questionable social policy.

host: The board is to use  
whatever tech is avail'  
to give the appear of known,  
risk + exclusion.

They assume that anybody  
that has a trait is going  
to have the worst possible  
outcomes for that trait.  
They will say that is a  
known risk for something  
awful.

~~von~~ von Recklinghausen  
disease - elephant man  
disease -  
dummest -

That is one of the most  
variable and we know -  
1 in 3000 - spots on skin.  
+ little growth.

That would be an example -  
we are going to have a genetic  
for it -

(spot?)  
a family w/ a disease.  
go to pink - selectively used

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Everybody is a risk  
for something so cool  
we are all going to do.

4000 genetic diseases.

I think it's prob true that  
everybody in the general  
pop has some genetic  
variation that puts them  
at risk for certain

infect  
cancer  
hypertension

The chance of picking  
someone out of the pop  
~~is low~~, + how many  
wrong is low.

will more have to change  
societal tastes? with  
or opposed.

currently now - B.P. above  
X/Y - you or me

higher risk group

They'll have to make some  
judgment on what constitutes  
too much suspect.

either they have to give up on  
insuring everybody, or it will  
harm

I think that in health care, if  
we will go away from private health  
insurance is going to be seen sort  
of redundant for our health  
insurance -

a high risk pool -

American Council  
of Life Insurance,  
1001 Penn Ave  
Wash., DC

The Potential Role of  
Genetic testing in Risk  
Classification

Robert J. Pokorski MD.  
Board VP of Lincoln Life Ins.  
Medical Dir. N.Y.C.  
212-427-3034.

What else is he going to say?

They say risk classif is good  
~~#~~ 617. because it puts  
people @ low risk

In the future, you're right,  
we'll have to decide what  
is high suscept.

William H. Alexander, MD  
UP + med College  
Life Reinsurance  
Co.

One of the biggest ins. com.  
in world

203-356-4444

20-30% who don't have ins  
It's partly much hard to  
find it

The mother had been diagnosed  
w/ Metastatic breast over 6  
years ago - treated - stage  
3c. She is self-employed.  
She has no health ins. & all  
her money is unemployed.

Obviously, not a genetic.  
What do we do? She has two  
young children in her care.

Mother is self-employed,  
\$30k / yr.

Nobody will insure her because  
she had cancer 6 years ago.

The next thing is  
contested, if you  
get identified in any  
way, you're in trouble

site?

From the methods you've  
used, there is no way to  
guess what the answer is.

We're designing a study to  
get at the power spectrum  
in sponges.

Peer: ~~██████~~

J.R. ERIC Lander  
Whitehead.

Peer Dorothy Nelkin  
Columbia  
School of Sociology

They conclude that if you have  
H.I., you should take a job  
that has group health.

I think people should be  
foss on the suitability, if it's  
time to work.

But under Regime paid for  
Health or group health should  
be ~~assumed~~ a major strategy  
if you want to do or not,  
no matter what your gender  
makeup is.

CF: general pop will over  
in next couple years.

Its very likely that I say  
point, The point you demand  
or have kids, They will.

Once you are ID as ill - gradually  
ILL treated ~~as~~ <sup>now</sup> HIV - you are treated  
in a diffrent way... may ok  
these people are not sick in  
an observable way, but they  
are treated as if they are ill.

Not all illness is genetic. There  
is this course, pretty fasted  
by the geneticist, that everything  
is genetic

~~can affect everybody~~

The 5 steps illustrate that  
many things are genetic that  
really aren't.

This is they want to find  
as many things as possible,  
do as many tests as possible,  
& create P's  
even if most determined  
genetic condition is unmodifiable.

Pku: if you inherit 2 genes  
for Pku, you have it @  
birth.

No phenyl - those children

That's a highly genetic  
determined trait that  
is highly modif.

test - the society desired  
hereditary disease removed  
& adopted.

sterile cell - many people who are  
sterile @ age 15,

In families w/ PKU, if they have  
a child born w/ PKU + D  
doing alright, These  
~~families never opt~~  
the vast majority of  
the people who have a  
child w/ PKU who  
have a son w/ PKU, do not  
opt for H.

- Screening @ birth + treatment

They don't eat or sleep.  
They don't eat this gesture  
fails to interfere w/ the  
reproductive process.

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Neil Gaiman 1992

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from *Wings*  
published  
Hans Christian Andersen  
Illustrated by  
Neil Gaiman