

健康保健和聋人大学生: 观察和教育的影响

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大家好。我是Carolyn Stern博士。我是纽约罗切斯特的一位聋人私人家庭医生。我今天讲的题目是健康保健和聋人大学生。我会给你们讲一个我自己和聋人的故事。让你们了解聋人儿童和他们的社会及教育。同时认识他们的经历对大学时期的健康保健的影响。我们还要讨论一些看法和资源,帮助你们掌握聋人学生健康保健的需求,使他们更好地完成学业。

Hello! My name is Dr. Carolyn Stern; I am a Deaf Family Physician, in private practice in Rochester, NY. My topic is Health Care and the Deaf Postsecondary Student. I will "tell you a story" about myself and the Deaf community. You will learn about Deaf children and their social and educational upbringing. You will then recognize how their experiences effect their health care needs while in college. I will discuss some ideas and resources. This will help you manage the Deaf student's health care needs, and allow them to continue their studies.



# 介绍

- •简介
- •告诫:从直接观察聋人病人和同事的口中只能了解到极少的研究信息
- •目标
- •总结
- •问题?

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关于这个话题的研究很少. 据我了解, 对听力需求的探索较多,但关于中国大学生健康保健需求的书面材料却很少.因此, 我会侧重介绍我在美国NTID和其他大学的直接观察和发现,以及从聋人和听力障碍学院收集的信息.大量事实证明,许多聋人学生对他们的健康保健需求和系统地了解很少.我对中国聋人的健康保健环境不会做任何假设,你们会发现我所讲的内容包含很广.我真心希望你们将我提供的信息和你们的亲身经历相比较.我了解普遍性可能适用中国聋人的文化,也可能不适用.

在你们对我刚讲的有所了解后,我现在就开始介绍总结我的观察.最后是现场问答.

在我演讲时,我会使用到"聋"一词. "聋"代表很多意思, 在我的演讲里指的是严重听力问题需要辅助设备才能进行交流, 包括需要用美国手语才能交流,以及那些需要助听器或其他辅助器材进行交流的人.

For this topic, there is little research available. As far as I was informed, audiological needs have been evaluated, but there is little written about health care needs of college-age students in China. Therefore, my focus will be my direct observations and findings, (as well as information from colleagues in the Deaf/Hard of Hearing field) in the USA, at NTID and other universities. Prevalent anecdotal evidence exists showing the naiveté of many Deaf students with respect to their health care needs as well as their poor understanding of the health care system. I make no assumptions about the health care environment for the Chinese Deaf, but you might find this presentation informative. I sincerely hope you can use my information to compare your findings and experiences in China with ours. I understand fully that generalizations may or may not apply to Chinese Deaf Culture.

As long as you understand this caveat, I will now discuss my objectives, summarize my observations, and I will answer questions when finished.

Throughout my talk, I will use the word Deaf. For your information, Deaf can mean many things; for this topic, I refer to the severe to profound hearing losses that require an assistive device in order to communicate. I include those that utilize American Sign Language to communicate as well as those who are Hard of Hearing who need hearing aids and other assistive devices to achieve effective communication.



### 目标

- •个人的经验
- •教育哲学观 (注意: 影响到健康保健)
- •聋对健康保健的影响
- •医科学校、医生和聋人
- •对聋人的高等教育和健康保健
- •预防及未来

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这些是这次演讲的目标。我从自己的教育经历开始讲起。虽然我的个人经历不能代表所有聋人,但你们可以认识到聋人并不特殊,就和你我一样。由于每人的家庭背景,文化和教育各不相同,经历也会不同。只要你们对此有所了解,你们就可以更好的帮助聋人实现健康保健。

美国有很多不同的教育哲学观,影响到聋人的健康保健。在各个时期交流的方式也不断变化。聋人需要不同的交流 方式,了解别人或被人了解,都会影响到健康保健。

可惜的是,很多时候医生或医护人员(护士,接生员,护理,理疗师,职业医疗师,牙医等)都没有受过培训,不理解如何为聋人或听力障碍人士服务。这些也会影响健康保健,特别对新入学的大学生,有健康问题无法得到解决,将影响到学业。

最后,我要讨论预防的工具和资源,以及聋人健康保健的未来。

These are the goals for this presentation. To give you a taste for this topic, I will tell you about myself and my educational experiences. While my personal experience does NOT reflect the experiences of all Deaf discussed, it will stress the important fact that Deaf people are individuals, just like you and me. Each person will have a different experience, based on family history and background, culture and educational achievements. Once you understand this, you can help the Deaf community receive excellent health care.

In the United States, there are different educational philosophies; these philosophies impact the health care of the Deaf. The pendulum in the US has shifted numerous times; each state varies as to their preferred communication method. In addition, <u>deafness</u> and the need for an alternative communication method, either to understand others or be understood profoundly affects health care.

Unfortunately, in many places, physicians and other health care professionals (nurses, midwives, physician assistants, nurse practitioners, physical therapists, occupational therapists, dentists and others) are not trained to understand and work with the Deaf/Hard of Hearing client. This, too, affects health care. Therefore, with the newly matriculated postsecondary Deaf student, if the student has health problems, these problems may hurt their educational experience.

Lastly, I will discuss prevention and provide some tools and resources; I will also discuss future options for health care and the Deaf community.



#### 背景

- •有风疹流行病引起的聋哑-1960年代
  - •行家说我很慢
  - •被建议说别指望学很多手语
- •随主流上学
- •在学校被辅导
  - •代记笔记的人
  - •听力训练
  - •学讲话

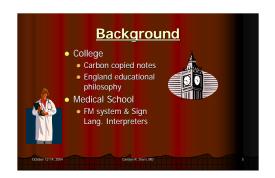
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我母亲怀我时,她的第一个孩子,我母亲感染了风疹。1960还没有疫苗。我8个月时,爷爷发现我听不见。他们找了医生。医生按经验检查没发现什么,告诉我父母我没事。当我14个月时,他们对我再次检查,发现我严重听力丧失,就给我配了助听器。他们告诉我父母我比较"迟钝",应该把我安置到聋人学校。他们还让我父母学习手语。我父母不同意。那时,聋人学校的教育水平不是很高。我家距离最近的学校有1.5个小时。父母决定如果我要上学,就到正常学校。之后,每周我奶奶会开车载我去语言病理学/听力病理学办公室。在我2岁时,我学会了说话和认字。虽然我右耳失聪,但带了助听器后我的左耳还有听力,我是听力困难的小孩。我的父母一直帮助我发展演讲和语言的能力。就算我父母给我读了超过100万本书我也不会觉得吃惊。

5岁时,我上了正常学校。我父母对纽约学校的设施不满意。5年级时我们搬家到马里兰。因为那里有聋人和听力困难学生的实习安排。有些聋人也上正常学校。有些课程只有聋人学生,有些是和正常学生一起。但是有些学生只参加全聋人的课程(单独教师)。在学校里,我可以像正常学生一样。每周我都要参加几次演讲治疗和听力训练。上课时,班上的几个同学会帮我复印笔记。我会坐在前排,可以专心听讲。为跟上课程,我会收到幻灯片的笔记。很多时候我帮老师放幻灯片,因为对笔记比较熟悉。

When my mother was pregnant with me, her first child, she contracted German Measles (Rubella). In the 1960's, there was no vaccine. At 8 months of age, my Grandparents recognized that I was not hearing things; they informed my Doctor. He empirically tested me, reportedly found nothing wrong, and reassured my parents and grandparents that everything was fine. When I was 14 months old, they retested me; sure enough, they discovered my severe to profound hearing loss and fitted me with hearing aids for the first time. They told my parents that I was "slow", not to expect much from me and place me in a residential school for the Deaf; they instructed my family to learn sign language. My parents disagreed. At that time, the residential schools' educational standards were not as high; we lived about 1 ½ hours from the nearest school. Instead, they decided that when I entered school for the first time, I would be "mainstreamed" at my home school. Until then, five days a week, my Grandmother drove me to the speech pathologist/audiologists office and back. There, at the age of 2, I learned to speak and even read. With my hearing aids, although my right ear was deaf, my left ear had enough residual hearing, that I functioned as a hard of hearing child. Both of my parents helped me with my speech and language development. I would not be surprised if my parents read me over a million books in my lifetime!

When I became 5, I entered the mainstream setting. My parents became dissatisfied with the services that the schools provided in NY; before I entered 5<sup>th</sup> grade, my parents moved to Maryland. There, they had a "cooperative" program for Deaf and Hard of Hearing students. Some Deaf went to a regular public school (mainstreamed). Some had classes with all Deaf students and mainstreamed for others, whereas other students were only in classes with other Deaf students (self contained classrooms). While in school, I was able to be completely mainstreamed; I received speech therapy and auditory training several times a week. For classes, selected students would carbon copy their notes for me in class. This process allowed me to sit up front, where I could focus on learning from the teacher. I received the "scripts" for the slide shows, to follow along with the class; often, I ran the slide show, since the script explained when to advance the carousel.



### 背景

### •大学

- •用碳粉复印的笔记
- •英国的教育理念
- •医科学校
- •调频系统 § 手语翻译

我以名列前茅的成绩高中毕业,进入俄亥俄的Case Western Reserve 大学。上学时,有专人帮我抄笔记。但我坐在前排,有些学生还向我借笔记呢!期间我还到英格兰的Sussex大学学习一年,因为他们讲英语,虽然有点口音。在申请面试时学院主任问我,"Carolyn,我想知道你如何在英格兰学习?这里的老师有口音.虽然他们讲的是英语,但和美国英语的表达方式和用词会有不同."我的回答是,"戴维斯主任,在 Case Western Reserve 大学,我遇到过很优秀的老师,结巴的英文老师,有强烈口音的外教,以及不会教书的老师!"戴维斯主任笑了,我很高兴.

在英格兰,考试很少多项选择.相反的,我们会对问题作研究,就某个话题写论文.我在Sussex大学写的论文比我在Case Western三年写得还多.这些经历使我很受益.我了解了国家健康系统,交了很多朋友.我学会如何有效使用图书馆,写一些科学和英语文学方面的论文.我很珍惜这次提高我词汇和写作的能力的机会.对聋人来说,读,研究和写作能力是接受高等教育的关键.

在我申请医科大学时,我小心地写个人说明.我觉得很有必要提到我是聋人,因为我认为是我和学校的资产.在17所申请的学校中,有3所接受我.我选择了芝加哥的西北大学,医学院.入学前,我给学校发了封信,要求有时会需要手语翻译.头两年,我参加了笔记发放系统,对每节课都有记录。然后我们把笔记发放给其他同学。同时课堂上还有FM调频系统。大学4年的第二年,我要求手语翻译。但是讨论课和手术课(带着面具)难度较大。助听器和FM调频系统也没有帮助.那时没有专业的医学手语翻译,我和翻译在课堂听讲中会自己发明一些医学方面的手语.

I graduated High School at the top of my class; I entered Case Western Reserve University in Ohio. While there, I had note takers for some classes. Since I sat up front in class daily, students approached me for copies of <u>my</u> notes! While in college, I opted to study at University of Sussex in England for a year, since they spoke "English", even if with an accent. My application process required an interview with my college Dean. During the interview, he asked, "Carolyn, I wonder how you will survive in England; the teachers will have accents. Although they speak English, there are expressions and words that are not "American" English?" My reply was, "Dean Davis, with all due respect, at Case Western, I have had wonderful teachers, an English teacher who stutters, foreign teachers with their accents and teachers who can't teach! Why will it be any different there?!" He laughed, and I had a wonderful time.

While in England, there were few multiple choice tests. Instead, we received questions to research and wrote papers on these chosen topics. I wrote more papers in England than in the 3 years at Case Western; it was a great experience for me. I learned about the National Health System and I made some wonderful friends. I learned to utilize the library effectively, and wrote profound papers for my science and English literature courses. I loved the unique opportunity to improve my vocabulary and writing skills. For many Deaf, reading, research and writing skills are critical for higher education.

When I applied to medical school, I carefully wrote my personal statement. I felt it important to mention my deafness, and present it as an asset to me and to the school. Out of 17 schools, I was accepted to three, and chose Northwestern University Medical School in Chicago, Illinois. Before arriving at Northwestern, I sent a letter explaining my deafness; that at some time during school, I might require sign language interpreters. The first 2 years, I participated in a note distribution system; I recorded each class. We then distributed the typed lecture to classmates who participated. I also had an FM system that helped in class. During my second through 4<sup>th</sup> years, I required sign language interpreters. Discussion groups and surgery (where they wore face masks) were the communication challenges. I could not follow with my hearing aids and the FM system. Since there were no "medically certified" interpreters, often the interpreter and I would create medical signs, while listening to the instructor at the same time!



### 背景

- •家庭医疗训练
  - •丰语翻译
  - •目标:同聋人和听力困难社区合作
- •小组和单独训练
- •不停的学习
  - •ACCME和发许可证

我选择家庭医疗作为我的职业.这种选择使我能接生婴儿,照顾儿童和大人.我可以是所有病人的家庭医生.如果对某个问题没有把握,我可以质询专家.

但是在住院医生实习期,我突然丧失了听力,还产生耳鸣.因为我不属于"聋人社区",很多困难发生了.一年里我的那只好耳朵听力时好时坏,最后两只耳朵都聋了.回顾起来,我觉得这些都有它发生的理由.我接受了耳蜗移植手术.加入了聋人社区.我对美国手语变得很熟练,意识到我的家庭医疗专业可以为聋人服务.(当然也可以为听力正常人服务,我没有歧视.)

毕业后,我加入2个医院.服务了超过2000名聋人病人.我走遍了美国和世界,为聋人,病人,医学专家,学校和大学提供医学信息,治疗信息,以我个人经历作榜样.

几年前,我在医学教育中遇到进退两难的情况.医生按要求每年要参加50个小时的医学教育.如果做不到,我们可能会失去在美国行医的执照.我找到ACCME, 医学持续教育考核理事会,他们专门负责考核CME, 即医学持续教育.我告诉他们持续教育的课程没有开设聋人服务.他们让我在大会上就美国残疾人法发言.经过4-5年的努力,很多CME都开设了残疾人课程.我对所取得的成绩感到很骄傲. ACCME对我的支持和信任使重要信息得以反馈,增加残疾人的课程.

For my career, I chose Family Medicine. With Family Medicine, I could deliver babies, take care of children and adults and I loved the possibilities. I could be THE primary physician for all patients. I would refer to a specialist if not comfortable with a specific problem.

Then, while in residency, I suddenly lost the rest of my hearing and developed tinnitus (a ringing in my ears). Since I was not "in the Deaf community", it was difficult for me. I endured one year of fluctuating hearing loss in my good ear. Subsequently, my loss stabilized to complete deafness in both ears. In retrospect, I feel there was a reason this happened to me. I had surgery for a cochlear implant, and then immersed myself in the Deaf community. I became fluent in ASL (American Sign Language) and realized that Family Medicine enabled me to provide health care to the Deaf community (as well as those who could hear...I did not discriminate).

Since graduating, I have been in 2 large group practices; I have seen well over 2000 Deaf clients. I have presented all over the US and internationally, providing medical information, practice information and role modeling with my personal story to those who are Deaf, as well as to parents, medical professionals, schools and universities.

A few years ago, I had a dilemma with continuing medical education. Physicians are required to take 50 hours per year of continuing medical education. If we don't, we may lose our license to practice medicine in the United States. I approached the Accreditation Council for Continuing Medical Education (ACCME), the organization responsible for accrediting CME (Continuing Medical Education) providers to provide CME for physicians, stating that providers were not making their courses accessible to those with hearing losses or other disabilities. They proposed that I present on the Americans with Disabilities Act (ADA) to their CME provider meetings. After about 4-5 years of doing this, many providers of CME have since made their courses accessible to those with disabilities. I am proud of this accomplishment; the ACCME's support and trust helped me provide critical information to improve accessibility.



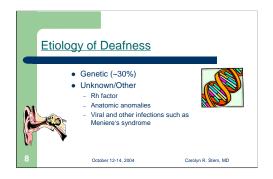
# 聋的病理

- •风疹或其他同怀孕期有关的病毒〔以CMV为例子〕
- •脑膜炎
- •同服药有关的(耳毒性药或其他)
- •外伤

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讲起来聋的原因很多.很多时候无法判断,但大多数和怀孕期感染TORCH有关,即弓形虫病,风疹,细胞巨化病毒,包疹等.其中最显著的是风疹.目前已经有风疹疫苗可以防止该病.脑膜炎也是致聋的主要原因之一.现在我们也有了脑膜炎疫苗.其他的原因还有:耳毒性的药物治疗(损坏中耳骨的听觉神经),外伤(例如车祸导致的头部受伤或怀孕期间器官外伤等).

To review, there are numerous causes of deafness. Most cases are unknown, but the most common causes are TORCH (Toxoplasmosis, Other, Rubella, Cytomegalovirus and Herpes) infections during pregnancy, of which the most famous one is Rubella. Now, there is a Rubella vaccine, which prevents most of these cases. Meningitis is another common cause of deafness. Now, for meningitis; there are vaccines to prevent these infections too. The remainder are: Medications that can be ototoxic (damaging to the auditory nerve or to the middle ear bones), trauma (such as a head injury from a car accident or trauma to the organs from pregnancy).



# 聋的病理

- •30%家庭遗传
- •不知名原因、其他
  - •Rh因素
  - •解剖学上不正常
  - •病毒或其他传染性的疾病如Meniere综合病症

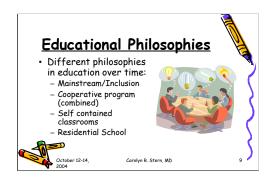
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30%的聋是来自遗传,包括connexin克乃辛基因和其他染色体变异,例如Down道恩综合征,糖尿病等.其他原因包括Rh不相容因素,中耳解刨异常,脑膜病症和各种病毒,通常伴有高烧.还有很多不知名的致聋原因.

有了疫苗,我们会看到更少的风疹或脑膜炎致聋的.但是,每年我们还会有大部分(千分之1或2)新生儿患有某种程度的听力问题.对他们我们应提供良好和方便的教育, 使他们能成为社会中成功的一员.我们还应该提高他们的健康保健.他们是我们的未来.

Thirty percent of deafness is genetic, which include the connexin gene and other chromosomal abnormalities, such as Down syndrome and Diabetes Insipidus. Other causes include Rh factor incompatibility, Anatomical abnormalities in the inner or middle ear, Menieres disease and numerous viral illnesses, often associated with high fevers. There are still many unknown reasons for deafness.

In the future, we will see less deafness from Rubella and Meningitis, due to the advent of vaccines. Yet, we still have a large percentage of children (about 1-2/1000) that are born each year with some degree of hearing loss. For these children, we need to commit to excellence and flexibility in education so that they can become successful members of our society. We need to improve their access to excellent health care. They are our future.



# 教育哲学

- •随着时间变化教育哲学有不同:
  - •主流、包含
  - •合作课程〔两个结合〕
  - •单独的教室
  - •寄宿学校

像幻灯片中所讲的,关于聋人的教育观各不相同.有一种是听力-口语相结合方法.聋的小孩会使用助听器,做耳蜗移植或其他设施来放大残留的听力.学校重点是使用听力-口语相结合的方法,最大程度发挥学生的演讲,语言和教育水平.大部分学校都采用这种方法.

另一种是双语-双文化的方法.虽然聋的小孩会使用助听器,做耳蜗移植或其他设施来放大残留的听力,但是重点还是使用美国手语或书写作为交流手段。

提高演讲固然重要,但重点应该在提高语言水平,包括美国手语,英语,教育和社会化.这些教育最好在住宿学校,但很多聋人学生离学校很近,每天来回.

另外一种方法介于中间.很多学生或家长不喜欢上述两种方法. 他们会加入合作的项目.有些学生只和聋人一起上课,有些部分和聋人部分和正常学生一起.大部分聋人学生在住宿学校上半天课,另外半天上正常课.

As this slide shows, we have different educational philosophies concerning the deaf. At one end of the spectrum, is the auditory-verbal method. The Deaf child may acquire hearing aids, cochlear implants and/or other tactile devices to maximize use of their residual hearing. The school focuses on maximizing the child's speech, language and education using auditory-verbal approaches. This occurs in either day school or the mainstream.

At the other end is the bilingual-bicultural method. The Deaf child sometimes uses hearing aids or cochlear implants for maximizing their residual hearing; but, the focus is on acquiring American Sign Language as the most acceptable language and primary mode of communication along with written English. Speech development is important, but more emphasis is placed on language development-learning both ASL and English, education and socialization. Often this requires a residential school environment, but some students live nearby and commute daily.

Another approach is somewhere in between. Some children and/or parents may not want either option; these students are often in a cooperative program. Some may have classes only with deaf children. Others have self contained classes (only deaf children) and mainstreamed classes (with children who hear), still others are fully mainstreamed. Usually this occurs in the mainstream; some students attend residential school half a day and mainstreamed the other half.



# 教育哲学

- •其他(比如,家庭教育)
- •父母介入的教育

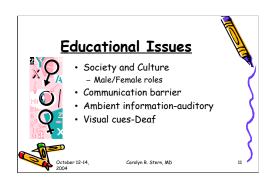
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最近,有些聋人参加私人学校或家庭教育,即父母们组织的教育项目.这种方式对聋人教育很有效.比起其他学校,人与人之间的交流更多.

父母的态度和参与对聋人儿童教育很重要.如果父母没有好的态度,不参与或提供帮助,会给聋人及整个家庭带来困难.我鼓励父母去帮助他们的小孩结识其他聋人小孩和大人,组织支持团队.这样聋人小孩觉得还有同伴,父母也能在交流中相互学习.父母不能把孩子当小孩,你们是聋人不能做这做那.注重结果.放手让孩子独立.只有这样,当他们离开家时,他们才能照顾好自己.父母和其他家庭成员要尽量和聋人小孩交流.我没有特别宣传的方法,你们应找到适合你们的交流方式.

Lastly, some deaf enroll in private school or are home schooled--their parents form groups with other parents for cooperative learning. These options are also effective for the deaf child; there is more personal interaction, which some schools cannot provide.

Parental attitude and involvement in the deaf child's education is critical. If parents do not have a good attitude, are not involved nor supportive, frequently the child AND the family suffers. I encourage parents to help their children meet other deaf children and adults and form support groups. This allows the Deaf child to realize that there are others "just like me", and the parents are able to network and learn as well. The parents should not "baby" the child, or tell the child "you can't do that because you are deaf. Focus on solutions. Allow that child to become independent. Then, when they leave home, they know how to take care of themselves, their health and have good study techniques. Parents and other family members should make every effort to communicate with their child. I do not advocate one particular method; the family needs to evaluate and use what works for them.



教育中的问题

- •社会和文化背景
  - •男女的角色
- •交流的障碍
- •周围的信息一听力的
- •视觉暗示-聋哑

\*\*\*\*\*\*\*\*\*\*

聋人教育存在许多问题.在教育界和不同文化中,存在男性和女性的角色不同.社会对这些角色的要求不同.例如,在美国和日本,男性在工业世界占主导地位,但女性的地位也在不断提高.通常女性都呆在家里.为什么角色很重要呢?在教育系统和家里,如果聋人小孩是男孩子,他们会给小孩压力让他成功.或者小孩会被送走,离开家庭. 对家庭来说,有个聋人小男孩比起小女孩更羞愧.在其他社会,女性需要工作挣钱.情况就不同.我们对这些教育界的微妙不同要有所了解,作出不同的反映措施.

除了教育方法不同,聋人的交流也存在障碍.聋人小孩没法理解所有事情,除非所有人都会用手语,或所有东西都可视,但这是不可能.大部分的周围信息都是听到的(而不是看到).对聋人就是一种障碍.聋人依赖视觉, 无论是书写的还是肢体语言.

With the Deaf, we have several educational issues. In the educational system and in many cultures, there exist male and female role models. Society and religions place different emphasis on these roles. In America and more so in Japan, for example, men tend to be more dominant in the working world compared with women although this gap is closing fast. Women are usually at home with the family. Why is this important? In the educational system and at home, if the deaf child is a boy, there may be increased pressure on that boy to succeed. Or, that boy may be shunned from the family and sent away. The family may be more ashamed having a male deaf child than a female deaf child. In other societies, the women need to work and earn money. In this case, there would be different challenges. We need to recognize and understand these subtleties within the educational system and be ready with possible solutions.

Regardless of the educational method, with Deaf, there exists a communication barrier. It is nearly impossible, unless everyone knows sign language or everything is visually displayed, for the deaf child to understand all that happens around him. Most ambient information is auditory (you hear the information as opposed to seeing the information); this therefore limits the deaf individual. The Deaf rely on visual cues, whether written, gestured or one's body language.



教育中的问题

•手语

对比

•口头、书面语言

手语不是书面语言,它和英语一样有自己的习惯用语和语法.但语言不同也会给交流带来挑战.例如,手语的习惯用语"火车走了对不起"(意思是你错过干刚才的谈话,我不再给你说一遍了),在英文就翻译得不好.但是,"差一丝"(意思是很接近)就能翻译得很好.还有很多手语对应同个英文意思,如"跑".有些英文词没法用手语来表示,只能拼写,或用故事来描述.这样交流的时间就增长了.

这些都会影响到健康保健,我接下来会进一步解释.

Sign language is not written; it is a visual language with its own idioms and grammar structure like the English language. However, languages are not alike and it can make communication a challenge. For example, the sign language idiom, "Train gone sorry" (meaning you missed the conversation, I'm not going to repeat it), does not translate well to an idiom in the English language, but "by a hair" (meaning a "close call" or a situation that was "almost a disaster") does translate well into English. Additionally, there may be many signs for one particular English word, such as 'run' (again, similar to some English words). Sometimes, there is no sign for a word; it either needs to be spelled, or a story is told to explain the word. These communication challenges lengthen the time required to express a concept.

This impacts health care, as I will explain later.



#### 交流的障碍

- •仅有30%-40%能从读口形中辨认
- •书面的信息总是被删节
- •成语和其他的细微差别不能区别
- •背景噪音和其他干扰

"交流障碍"对教育和健康保健都很重要.很多词语看起来或听起来都很相似.如果聋人对讨论的题目不了解,他们就很难参加讨论.我认为在中文也是一样.中文里也一些拼写和发音相似的词汇.如果改变一个词的拼写或发音可能表达的就是不同的意思! 英语的"mat, pat, bat" 唇部动作很相似.但是如果在讨论棒球,可能会用到"pat, bat", 而不是"mat". 所以讨论的题目是很关键的.如果没有上下文或残留听力,依靠读口形只能理解30%-40%.

当聋人不明白时,他们会要求你写下来.但是如果你在讨论线性代数或物理实验,书写谈话就比较困难.聋人主要依赖视觉而不是听觉,所以画图帮助很大.大部分书写谈话都很短.比如,"我要你到我办公室那你的药,并讨论一下副作用",写下来可能成为"到办公室讨论药",甚至有可能短到很难理解.

我前面有提到,习惯用语和语言的微妙差别有时很难翻译.需要花时间解释.课堂只有40分钟,办公室辅导可能也只有15分钟.时间可能要作调整已适应聋人的需求.

背景噪音,音乐和不良照明都会影响学习和谈话.其他分散注意力的因素还有:嚼口香糖,边吃边聊,留胡须盖住嘴巴等,都会影响到良好的交流.

The concept of the "communication barrier", is critical in education as well as in health care. Many words look or sound the same. If the discussion topic is unknown, group conversations can be confusing to the Deaf. I am sure there is a parallel in Chinese. I would not be surprised if there are Chinese words with similar spelling, and pronunciation—that if you change the inflection or accent within the word, you might say the wrong thing! In English, words such as mat, pat and bat all appear to look the same on the lips; however if you are discussing a baseball game, unless Pat is up to bat next, I would venture to say that pat and maybe mat would not apply in a baseball discussion. Conversational cues are critical. If there are no contextual clues or residual hearing ability, only 30-40% is truly understood by lip-reading alone.

When the Deaf don't understand something in conversation, often they ask the person to write it down. While this seems ideal, if you were talking about linear algebra or experimental physics, writing your dialogue would be a challenge! Since Deaf rely heavily on visual as opposed to auditory information, it may help to draw a picture during the conversation to explain a concept. But, most written information is shortened. Instead of writing, "I need you come to my office to get your medications and explain side effects that you need to understand", often one would write, "Come to office to discuss medicine", or the writing may be unreadable.

As mentioned before, idioms and other language nuances may not translate well; it takes time to explain concepts. Time counts; classes may be 40 minutes in length and an office visit may be 15 minutes. If the concepts cannot be explained within the allotted time, it affects health care as well as education. Schedules may have to be altered to accommodate this need.

Background noise, music, and improper lighting affect learning and conversation. Other distractions include chewing gum, eating while talking, beards, mustaches, and covering your mouth. All can distract from good communication.



### 交流的障碍

- •视觉同听觉作比较
- •父母,小孩,学校和同学和交流
- •专业医生和交流

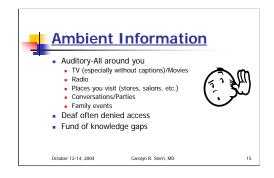
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聋人儿童的社会环境会影响交流.很多聋人不知道如何保证自己得到足够的交流.很多聋人依赖同伴来获得信息,有时信息并不准确.为什么?因为很多父母,家庭成员,医生,学校和大部分人都不知道如何和聋人交流. 到目前为止,很多人还认为聋人不能做任何事,因为他们是聋人.这种观点后果很糟糕.很多聋人高中毕业后离开家都不知道如何照顾自己..他们不会做饭,洗衣或学习.很多人不懂如何与医生预约,或看医生.我们要教育聋人使他们离家能独立,懂得照料自己.

医生也有责任.当聋人小孩长大可以和医生交谈时,如果医生还是只和父母交流而忽视聋人小孩,小孩就会觉得没有能力.小孩会对自己的健康不关心.他们以为父母会照顾自己的.当聋人小孩认为不必对自己的健康负责的时候,通常,第一次离开家是他就不了解自己健康保健的需求.

The Deaf child's social environment can affect communication. Many Deaf do not know how to advocate for themselves to ensure they receive adequate communication. Many Deaf rely on peers for information, even if the information is misleading. Why? Because parents, family members, physicians, schools and many others don't know how to communicate with the Deaf. Many, even today, feel that Deaf "can't do anything because they are deaf". This "babying" of the deaf child has undesirable consequences. Many Deaf leave home, not knowing how to take care of themselves when they graduate high school. They don't know how to cook, do laundry, or study. Many don't know how to make an appointment with a primary care physician, or know why they should see their doctor. We need to empower the Deaf so that when they leave home, they are independent and can fend for themselves.

Physicians are also guilty of "babying" the Deaf child. When a child is old enough to communicate directly with the doctor, if the doctor communicates with the parents and ignores the deaf child, the child feels powerless. The child feels it is not important to learn about his health. He knows Mom and Dad will take care of it. When the child is not held accountable for his health care, usually, he won't understand his health care needs when he leaves home for the first time.



# 周围的信息

- •到处都是听觉信息
  - •电视(尤其是没有字幕),电影
  - •收音机
  - •你所到的地方〔商店,发廊等等〕
  - •对话、派对
- •聋人经常拒绝获取信息
- •知识缺陷的经费

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虽然听到的信息可能被翻译错误,但还是很重要.周围信息就是你身边的所有信息。美容沙龙里听见隔壁的顾客谈她最喜欢的医生,如何找到最好的医生治疗她的膝盖问题。听到收音机里介绍最新的戒烟药,而且不含盐碱。爸爸妈妈在讨论表妹connie, 她住院了,切除阑尾。这些是可能发生在任何地方:聚会,电影,记录,办公室的谈话等等。

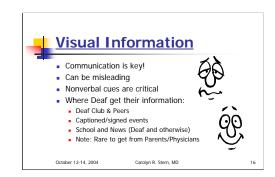
因为这些信息是听来的,而不是看来的,很多聋人没有办法得到这些信息。这也是为什么聋人的健康保健知识和我们有距离的原因之一。

While auditory information can be misinterpreted, the information can be critical. Ambient information is that which is all around you. One hears the customer next to you at the beauty salon, talking about her favorite physician and how she went to the best specialist for her knee problem. One listens to the radio about the newest medicine to help people quit smoking and it doesn't have any nicotine. One listens to Mom and Dad explain about cousin Connie—that she is in the hospital due to a stomachache and had her appendix removed. This happens everywhere—parties, movies, documentaries as well as conversations at your workplace.

Because this is information you <u>hear and don't see</u>, many deaf are denied access to information we take for granted. This is one reason why deaf have gaps in their knowledge base with regard to health care and other subjects.

### 周围的信息

- •交流是关键
- •有时会误导
- •非语言的暗示有时很关键
- •聋人从何处获取他们的信息
  - •聋人俱乐部和同学
  - •字幕、有带手语的事件
  - •学校和新闻(聋人和其他)
  - •注意: 很少从父母和医生那里获取信息

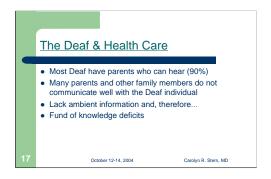


你可能会说,"聋人可以看到一些我们看不到的东西"。这可能是真的。但交流还是提高聋人教育和健康保健的关键。就算是可视的信息,例如肢体语言,也可能令人误解。聋人小孩看到妈妈捂着肚子吃镇痛药,他可能意识不到妈妈还有头痛。利用视觉作为线索,小孩可能错误地认为,肚子痛的时候要服用镇痛药!几年前,我遇到一位聋人病人抱怨肚子痛,当我问她服用什么药时,她说,"镇痛药,因为我妈妈肚子痛也吃镇痛药。"但我了解到她妈妈有偏头痛,这就解释服用镇痛药的原因了。我告诉这位聋人病人肚子痛不能吃镇痛药,反而会使肚子更不舒服。非语言的提示也很关键。看到你的眼睛或眉毛的动作,(而不是你的语调)聋人会意识到你在提问题或陈述一件事情。

听不见,那么聋人在哪里怎样得到信息呢?在聋人电话,计算机,放大电话,有字幕的电视或电影发明之前,聋人会聚集在聋人俱乐部。在那里,他们打牌,玩bingo游戏,募捐,会议,写时事通讯,聊全美聋人等。很多城市还有他们的聋人俱乐部。聋人会从同学那里得到新闻,从同事那里得到体育时事。现在聋人使用即时信息和文字传呼机而不是聋人电话。当我年轻的时候,我们常常看有字幕的邦德007影片。有时我们会在家和聋人朋友过"电影夜"。现在,几乎每个州都会有字幕电影院。聋人还可以从聋人出版物中得到信息。他们不再依赖从父母或医生得到信息。

"Well," you say, Deaf can "see things we can't." While this may be true, communication is central to improving the education as well as the health care of the Deaf community. Even visual information, such as body language, can be misleading. For example, Mom has a migraine headache and feels nauseous. The Deaf child sees Mom holding her stomach and Mom taking Ibuprofen. That child may not realize that Mom also has a headache. Using only visual cues, the child may wrongly believe, that when their stomach hurts, they should take ibuprofen to relieve the pain! Several years ago, I saw a Deaf patient who complained of stomach pain. When I inquired about her medications, she said, "I take ibuprofen, since my Mother took it for stomach pain." Once we realized her mother had migraines, I then explained why her Mom took ibuprofen. I then demonstrated why ibuprofen was NOT a good pill to take for an upset stomach, and in fact, would make her stomach pain worse. Despite their problems, nonverbal cues are still critical. Deaf people know when you are asking a question or making a statement, by watching your eye and eyebrow movements (not by the tone of your voice).

If they can't hear information, where and how <u>do</u> Deaf get information? Before TTY's (Teletypewriters for the Deaf), computers, volume amplified phones, captioned TV's and movies, the Deaf congregated at the Deaf Club. There, they played cards, bingo, had fundraisers, meetings, wrote newsletters and shared news as well as gossip about Deaf people all over the US. Many cities still have their Deaf Clubs. Deaf people rely on news from their classmates at school and sporting events as well as their colleagues at work. Now, Deaf will use instant messaging and text pagers instead of the TTY. When I was younger, we used to watch "subtitled" James Bond movies on huge 16 mm reels; we would have "movie night" at our house with Deaf friends. Now, movie theaters in nearly every state have captioned movies or rear window captioned movies. Also, Deaf people receive information from deaf publications. Rarely do they rely on information from parents and physicians.



### 聋人和健康保健

- •许多聋人的父母都是有听力的正常人(90%)
- •许多父母和其他家庭成员不能同聋人交流
- •缺乏周围的信息和,因此。。。
- •知识缺乏的经费

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虽然30%的聋是因为基因,但是90%聋人的父母听力还是正常。这就给交流带来了挑战。如果家庭重视交流,提供接触信息的良好环境,那么聋人小孩就能茁壮成长。这并不代表父母必须学会某种特殊交流方法,而是创造一种简单的环境,家人和聋人小孩能相互交流,觉得自己是家的一分子。

这种现象不断得到改善,但是很多父母或家人还是没有学会和聋人交流。聋人还是没办法得到周围信息,他们的知识面还是不够。

有趣的是,研究表明,聋人父母的聋人小孩有很强的读写能力,文化水平。他们的知识欠缺较少。

Although approximately 30% of deafness is genetic, 90% of deaf have parents who can hear. Immediately, this creates a situation where communication is a challenge. If communication matters to the family, and they create a supportive environment with information access, the child will thrive. This does not mean that the family needs to learn a particular method for communication. This means simply an environment in which the family and the deaf child can communicate and all feel part of the family.

The situation in most families has improved slowly over time; still, many parents and other family members have not learned to communicate with the Deaf individual. The ambient information is frequently not relayed to the deaf child, and once again, the Deaf individual suffers from deficits in his fund of knowledge.

Interestingly, research studies show that Deaf children with Deaf parents, have strong literacy skills as well as cultural and critical literacy levels. They have fewer knowledge deficits.



# 聋人和专业医生

- •专业医生教你如何去治疗
- •在医科领域很少有有关聋人和聋人文化这方面的知识〔护士、药方等等〕
- •许多都不懂听力敏度图或暗示同交流的关系
- •很小的残疾率〔大概占人口的1-2%〕

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让我们来看看医学人员。他们应该是"助人为乐的有同情心的人"。过去的10年,医生和健康保健人员的生活发生了改变。以前医生会到你家里给你看病接生,现在你要到他们的办公室里。在实施医疗保险之前,医生可以接受尽可能多的病人,他们的生活很舒适。这种情况已经不同了。现在医生一天看大概20-30个病人,每个病人只花5-7分钟。医生和其他专业医疗人员需要使他们的老板满意,医院满意,保险公司满意,会计满意,律师满意,同时也要使他们的家人满意!

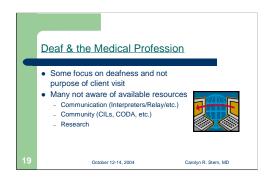
我在医科大学学习时,从来没有上过"聋人文化"这门课。我们只听了1个小时的听力敏度图介绍,了解病理专家和听力矫正专家的作用。这并不能教会医生如何对待聋人病人。医生还是无法读懂理解听力敏度图。直到最近我们才接触到病痛管理的观念,而不是每个心脏病都用CPR来处理。医疗专业人士受的教育是治疗修复问题,对他们来说,聋也需要治疗。包括耳蜗移植或其他疗法。

聋是影响范围较小的残疾。美国有大约2千8百万人有着某种程度的听力丧失。这大约占人口总数的1-2%! 很多医生,除非你住在纽约罗切斯特,一辈子都没有遇到过聋人病人。

Let us look at the medical profession. They are supposed to be "caring people who desire to help others." In the past 10 years, physicians and other health care professionals' lives have changed. Where once General Practitioners came to your home to take care of you or deliver your baby, now, those same physicians have offices you need to visit. Before health insurance or malpractice insurance, physicians could see as many patients as they wished, and could live comfortably. The medical field is no longer the same. Physicians now see 20-30 patients a day, allow only 5-7 minutes with a patient, and every minute counts. Physicians and other professionals now need to satisfy their boss, their hospital, their insurance company, their accountant, their lawyer (malpractice company) as well as their family!

When I went to medical school, there never was a course on "Deaf Culture". We received a one hour presentation on the audiogram, as well as what speech pathologists and audiologists do for doctors. This does NOT prepare the physician or other health professional to have Deaf as patients. It did not prepare physicians to read, understand and interpret the audiogram with implications for communication. Not until recently have we embraced the concept of pain management and hospice, as opposed to treating everyone with terminal illness or a heart attack to CPR (cardiopulmonary resuscitation). In general, medical professionals are taught to cure, fix or treat the problem, and to them, deafness needs treatment. This treatment includes cochlear implants and other devices.

Additionally, deafness is a low incidence disability. In the US, about 28 million people have some form of hearing loss. That number is only 1-2% of the population! Most physicians, unless they live in a city with a high concentration of deaf individuals like Rochester, NY, will never meet a deaf person in their lifetime.



### 聋人和专业医生

- •因此,难度发展到硬币的两个面
  - •聋人因为从前的经历对专业医生感到不舒服
  - •专业医生也对聋人感到不舒服
- •结果:许多聋人对健康保健的认识很糟糕

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医生遇到聋人病人是很尴尬。他们不知道怎么办!很多医生认为聋人需要治疗,或他们不希望聋。医疗人员可能会替聋人觉得悲哀。有些医生会遇到不愉快的经历,因为他们听不懂聋人说话。如果聋人病人没有转好,医生就会认为聋人没有遵照医嘱,而实际上很多时候是没有足够的交流。

有位聋人妈妈解释为什么把她小孩从其他医生转到我这里。"每次我带儿子去看医生,不管是例行检查还是喉咙痛,那个医生都问我们要不要做耳蜗移植。第一次我告诉医生我们考虑了,决定不做因为不适合我们的小孩。但是那个医生并不放弃!最后我告诉他,我带小孩来是因为他喉咙痛,而不是需不需要耳蜗移植!"那个医生只注意到我小孩的聋,而不关心我们来看医生的真正目的.

医生没有意识到可供他们和病人的社区资源.很多人不熟悉描述聋的语言.他们可能使用"聋哑,听力受损"等词汇,而不是美国通用的"聋或挺立障碍". 当医生写诊断书的时候,他们还把聋人描述成聋哑! 他们不熟悉手语,不知道可以使用"中转服务",通过接线员来和聋人交流.他们也不懂得使用社区资源,例如"CIL独立生活",CODA聋人的小孩组织和聋人俱乐部. 医生们也不知道利用研究成果.

Physicians feel awkward when they meet a Deaf person. They don't know what to do! Some physicians believe Deaf want a "cure" or are unhappy with their deafness. Health professionals may feel "sad" or guilty about the client's deafness. Some physicians have had bad experiences with deaf clients. Some can't understand the deaf person's speech. If the Deaf client did not get better as expected, physicians may feel their client did not follow instructions, when in fact, adequate communication was not provided.

One deaf patient's mother explained why she brought her child to me and not their former physician. "Every time I brought my son to the doctor, whether a well child exam or a sore throat, the doctor would ask if we had considered a cochlear implant for him. I informed the doctor on our first visit that we considered it, and our family decided it was not the right choice for our son. The doctor would not give up! Finally, we told him, "we brought our child here because he has a sore throat, NOT to see if he needs a cochlear implant!" This child's doctor focused on the child's deafness and a cure; not the reason for the child's visit.

Physicians are not trained nor are they aware of community resources available to them or their deaf clients. Many are not familiar with language used to describe the Deaf. They may use Deaf-Mute, Deaf-and-Dumb or Hearing Impaired, instead of Deaf or Hard of Hearing which are preferred terms in the US. In fact, when physicians assign a diagnosis code for a patient visit, the term deaf-mutism is still considered a valid code! They are not familiar with Sign Language interpreters, "relay services", where you can talk to a deaf person through an operator who either types or signs your message to the client. Nor are they aware of community resources, such as Centers for Independent Living (CILs) or support groups such as Children of Deaf Adults (CODA) and Deaf Clubs. They may not be aware of available research.



#### **聋人和专业医生**

- •因此,难度发展到硬币的两个面
  - •聋人因为从前的经历对专业医生感到不舒服
  - •专业医生也对聋人感到不舒服
- •结果: 许多聋人对健康保健的认识很糟糕

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我们知道医生和聋人病人在一起觉得不舒服,聋人也有同感,因为他们有过不愉快的经历.聋人也应该为交流问题负责任。比如,在嘈杂的餐馆里听不见的时候,当你明白对方的意思你就会点头表示。聋人很会这种技巧。甚至当他们不明白医生或老师时候,他们也会点头表示!这样医生会以为聋人明白了,而实际上信息并没有传递清楚。有些聋人不想给医生添麻烦,就不要求手语翻译,实际上翻译不仅只是帮助聋人,也同时帮助医生。

聋人换医生的原因有: 医生没有配手语翻译,医生较生硬没有花时间解释,医生有口音聋人不明白,医生的肢体语 言表明对聋人病人不耐烦 (有时候不是真的-有可能医生刚查出病人有癌症)。

因为有这些经历,很多聋人不清楚自己的健康保健需求。他们不知道何时应求助于医生,保险,多长时间应看一次医生等。这些地方都有待提高。

我们没有像是用笔和纸那样频繁使用手语翻译。我们和手语翻译合作,和聋人病人进行交流。作为医疗专业人员有责任保证有效的交流。

We understand that physicians are uncomfortable with Deaf clients due to bad experiences. Deaf, too, are uncomfortable with medical professionals due to bad experiences! Deaf individuals, too, are responsible for their communication failures. For example, how many of you, while talking with someone in a noisy restaurant, will not hear everything, but to keep things moving, will "nod" your head as if you understand the other person completely? Well if you do, Deaf people are "masters" at this technique. Even if they don't understand what a health professional or teacher says, they will "nod" their head in a "yes" fashion to show understanding! This makes the physician think that the Deaf person understood him, when in fact, the message was not clear. Some Deaf do not want to "burden" their physician with the "hassle" of a sign language interpreter, when in fact, the interpreter is there for the physician as well as for the deaf person.

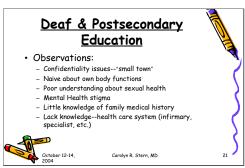
For the Deaf, here are some reasons why they change physicians: Doctor won't provide a sign language interpreter, Doctor is abrupt and won't take the time to "explain" things, Doctor has an accent they don't understand, and the doctor's body language shows he is "frustrated" with the deaf client (even if not true-the doctor could be upset about a new cancer diagnosis, for example).

Because of these experiences, many Deaf do not understand their health care needs. They don't understand what happens when you call a doctor's office, insurance policies, how long a visit with the physician lasts or why you should see the doctor. These are areas where there is room for improvement.

With regard to interpreters, we don't "use" an interpreter like we "use" a pen to write on paper. We work with the sign language interpreter, who is a professional, to help facilitate communication with the deaf client. We, as health care professionals and educators, are ultimately responsible to make sure that communication happens effectively.

聋人和高等教育

- 观察点:
  - •保密的问题一"小镇"
  - •对自身的功能非常无知
  - •对性的认识非常差
  - •心理健康障碍
  - •对家庭医疗记录非常无知
  - •缺乏知识一健康保健系统〔医院,专家,等等〕



在美国,我和其他人发现和聋人大学生打交道有些共同点。但并不是所有聋人学生都是这样的,有些地方仍然是没有办法调查到的。聋人社区和一个小镇很相似。聋人体育,俱乐部,电子邮件,聋人学校,大学等通过聋人之间的 交流流传很快。

另外,由于交流上的困难,很多聋人学生不理解自己身体的变化。他们不知道如果不多吃水果,蔬菜和水,他们会 便秘,肚子疼。他们可能不知道

感冒要10天左右才能康复。 他们甚至不知道只要1次性生活就可能怀孕。他们对健康保健的选择也不清楚。在美国很多聋人把急诊室当成是医生办公室,因为那里有手语翻译服务。他们不会利用家庭医生,而是依靠朋友来获取信息 ---- 因为他们和父母及医疗人员交流很差。

精神医疗保健也有问题。虽然大学里有心理医生,但很多聋人还是到校外就医,或根本不就医。他们不去学校的"smith医生"办公室,因为他们不信任他们的同学。他们不想人别人知道自己有问题,就不去寻求帮助。同时,聋人也许不知道自己有消极症,或极端化。他们不会去就医,直到病情很严重了。

当我接受一个新病人时,我会了解他的全部医疗历史。这包括家庭医疗史,个人经历过的手术住院等。大多数人不知道自己的父亲需要特殊饮食,或妈妈有哮喘或糖尿病。他们很少会知道亲戚和祖父母的病历。更令人担心的是有时候他们甚至不知道自己肚子上的伤疤怎么产生的。从伤疤的位置,我通常可以看出原因;有时我还会看他们的旧病历,听他们讲话,看看在过去的10-20年了发生了什么事。为了将来,他们必须了解自己的病史。

聋人需要帮助来有效的使用医疗设施。有问题应找到答案。学生医疗中心可以提供什么服务呢?为什么我需要看专家门诊?专家是干什么的?什么时候我该看急诊?聋人病人一般是有很多问题才开始看医生。有时需要交谈5分钟才会明白来看医生的目的。我们应该教他们如何有效利用医生和他们自己的时间。

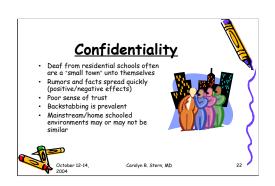
In the US, there are some common observations that I and others have recognized when working with the deaf university student. Not all students will fit these observations; again, research is lacking in this area. The Deaf community is very similar to a small town. Deaf sports, Deaf clubs, email, Deaf schools and colleges with large numbers of Deaf allow word of mouth (and hand) to spread rapidly.

Additionally, due to communication barriers, many Deaf students do not understand their own changing bodies. They may not realize if you don't eat enough fruits, vegetables or drink enough liquids, they will become constipated and have stomach pains. They may not understand that it takes 10 days to recover from a "cold". They don't realize that it only takes one time to get pregnant. They don't know their health care options. In the US, many Deaf use the Emergency Room as a doctor's office, because they provide sign language interpreters. They don't understand the concept of the primary care physician and rely on peers for information—not their health providers or their parents due to poor communication.

Mental health is another concern. The University may have therapists on site, but many Deaf will see therapists "outside" the university or not at all. The negative stigma is harsh; they won't go to "Dr. Smith's office" at the University, because they don't trust their peers. They don't want others to know they have a problem, therefore, they won't get help. Also, the Deaf may not realize they have depression or bipolar disorder, for example; they don't know how to get help when needed, until too late.

When I see a new patient, I like to get a complete medical history. This includes their family's medical problems as well as any personal surgeries or hospitalizations. Often, the Deaf don't know Dad is on a special diet, or that Mom has asthma and diabetes. They rarely know why a relative died or their Grandparents' medical problems. More concerning are stories from deaf clients where they have a scar on their stomach, but are not sure why. I can usually explain the surgery, based on the scar location; usually, I gather old records, listen to their story, and explain what happened to them 10 or 20 years ago. They need to know their medical history for their future.

The Deaf may need assistance in using health services effectively. Questions need to be answered. What services can the student health center provide? Why would I need a specialist? What does that specialist do? When should I got to the emergency room? Deaf clients often start their office visit from "the beginning of all their problems". Five minutes into their story, they finally state the real reason for the visit. We need to teach them how to best use the physician's time as well as their own.



#### 保密性

- •寄宿的聋生经常组成一个"小镇"
- •流言和事实传播很快〔有好也有坏影响〕
- •信任感差
- •背后陷害人现象普遍
- •主流、住家学生的情况可能不同

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虽然聋人分布很广,但聋人社区象"小镇"一样.华盛顿发生的事情过几分钟或几天就会传到加利福尼亚的聋人.他们知道谁离婚了,谁被解雇了,谁欺负谁了,还有结婚,生子,执业等等.这对医疗领域影响很大,因为不再有保密性.我们没有办法制止在医院里讨论病情,但可以不和其他聋人或家人讨论病情,

这样就可以提高聋人的信赖.很多时候,聋人的父母,女儿或兄弟姐妹会给聋人当翻译或信息的传递者.有些医生不清楚这种情况,他们会把病情告诉聋人的家人.这对2-5岁的聋人病人不会有什么问题,但是对青年或者大学年级的就不适用了.在医疗检查是青年或者成年聋人病人不希望家人在场.他们希望和医生直接交流.我们要使聋人对医疗系统产生信赖.

我又遇到过陷害的情况.有几个聋人问我行医执照是否被暂停了.还有人问我是不是"真的"医生.当有人成功的时候,由于行业竞争,就会妒嫉,不信任.这样会影响聋人接受更高的教育.他们认为"他们是聋人所以无法成功".结果是有些聋人制造流言,破坏他们名誉,进行陷害.

值得注意的是,主流,私人学校或者在家受教育的聋人学生和住宿或走读的学生经历会有不同.

The "small town" atmosphere is prevalent in the Deaf community, even though Deaf live everywhere. People in California know what is happening in DC or in Chicago within minutes or days. They know who got divorced, who was fired or who abuses others, as well as the positive events of marriage, children and careers. This impacts the health care field where confidentiality is critical. We can't stop health care discussions in our office waiting rooms, but we can improve their trust in the health system by not discussing their care with other deaf or their families. Often, the parent, daughter or sibling act as translators or communicators for the Deaf individual. The physician, unaware of the ramifications, will give the family member information to "help" the deaf patient. While that may be acceptable for a 2 year old or a 6 year old, it is not acceptable with teenagers and college age students. Teenagers and adults usually don't want family in the office during an exam. They need and deserve direct communication with the physician. We need the Deaf to "trust" the health care system.

I encountered "backstabbing" when I first started my practice; several Deaf asked me if my medical license was suspended. Some asked if I was really a "real doctor—an MD". When a community has been excluded or oppressed by a larger community, often disbelief and jealousy occur when members succeed. This jeopardizes higher education for the Deaf. They feel "they can't succeed because they are deaf". As a result, some Deaf create false rumors and destroy reputations with backstabbing.

Be aware that Deaf in the mainstream, in private schools or who are home schooled will have different experiences than those in residential or day schools.



# 在上大学前

- •主流学生同寄宿或住家学生
- •对将来健康照顾需要的影响
- •老师和翻译是否有效地交流了健康信息
- •教育资料是否可及

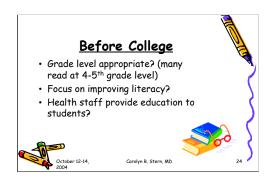
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在我们评判高校聋人健康保健系统的时候,前期的经历是很重要的.聋人知道什么?这样我们才能提供进一步的教育.学生入学之前学习环境和知识背景不同,他们会有不一样的个人健康要求和不同的将来问题.

学生以前的老师和家人是否有效的传达健康信息?聋人学生是否能够得到班级分配的资料?聋人是否理解资料了的词汇?

Before we evaluate health care needs of the deaf college student, prior experience is critical. What do they already know? Then, we can provide further education. Students will enter college from different school environments and will differ in knowledge regarding their personal health and future concerns.

Were the student's former teachers and parents able to communicate health information effectively? Were the materials distributed in class accessible to the deaf student? Did the deaf student understand the vocabulary used in the materials provided?



# 在上大学前

- •分级别正确吗? 〔许多阅读技巧在4-5级阶段〕
- •要着重提高读写能力?
- •保健职工要给学生提供教育?

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我们了解到英语并不是多数聋人的母语。如果他们用手语作为交流手段,那他们就要花时间提高听和写的能力。总体来说,聋人的英语阅读水平相当于4-5年级学生。但如果聋人学生的父母也是聋人的话,他们的文化水平和听力正常的学生就没有区别。

我们应该了解一下在提高美国手语的同时也应该提高英语水平?如果是的,学生在这方面就会提高。学生医疗中心或学校的医生是否参与学校医疗教育课程的鉴定?这些信息在新生入学时对学生医疗中心是很有帮助的。

We know that for many Deaf, English is not their first language. If they use Sign Language to communicate, we understand it takes time for reading and writing skills to develop within the different educational philosophies. On average, many deaf do not read better than 4-5<sup>th</sup> grade level English. Here, again, if a deaf student has deaf parents, usually literacy is on par with those students who can hear.

We need to know if there was an emphasis on improving English literacy as well as ASL literacy? If so, the students will do better overall. Is the student health center nurse or physician at school involved and vested in evaluating the school's health curriculum? Do they assist with educating the students about health? This information is helpful to the Student Health Center when the student enters college.



### 预防和将来

- •什么是健康问题
- •如何来解决这些问题
- •建立一套体系

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总体来说,聋人的健康保健问题和听力正常的学生差别不大。例如,在美国患消极症的聋人学生比例和正常学生是相同的,患感冒的情况也是一样的。不同之处在于治疗和侧重点。在年检的时候,如果医生检查身高体重,询问疫苗,抽烟和性生活,但不检查这一方面,聋人学生会认为身高和体重是最重要的。但是,如果检查人员和聋人详细交流询问关于疫苗,抽烟和性生活的问题,并且测试情绪和血液,聋人就会意识到它们的重要性了。

如果中国没有聋人和其他学生健康情况的比较的研究,那么我们就要开始问问题了。我们如何才能预防大学生的健康问题?他们入大学后会有哪些健康问题?

抛开研究不谈,大学里的医务人员知道危机发生和情况的也是很少。医务人员的教育和学生的教育一样重要。有系统解决这些问题吗?如果有,这些系统对学生开放吗?应该和谁联系?

In general, health care issues in the Deaf do not differ much from their hearing counterparts. For example, in the US, the prevalence of depression is the same in the Deaf population as in those who can hear. The flu is as prevalent in the Deaf population as in those who can hear. The differences are with treatment and importance associated with the health issues. At an annual exam, if a doctor checks height and weight, asks about immunizations, smoking and sexuality, and the exam is not accessible, the Deaf student might only feel that height and weight are important. But, if the examiner communicates well with the Deaf, inquires about smoking, sexuality, the student's mood and blood tests, then the student understands the importance of all these issues.

If there is no research on the health status of the Deaf student compared to other students in China, then we need to start asking questions. How do we prevent health problems in college age students? What are the health issues when they arrive in college?

Regardless of research availability, the university health staff know which crises happen regularly and which situations are rare. Health education for the staff is as important as health care for the student. Is there a system to address these events? If so, is this system accessible to all students? Who is the contact person?



### 健康保健的问题

- •交流
- •健康教育、保健
  - •男性角色问题
  - •女性角色问题
  - •聋的问题
  - •听力障碍问题
  - •人际关系问题

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设定好聋人健康保健系统后,我们应解决交流的问题。系统应做什么来提高交流?不仅仅位聋人学生,也为全体学生。我们知道楼坡比起楼梯更方便于坐轮椅的人。我们也知道楼坡也方便于带小孩的母亲,有关节炎的人,移动车等等!听力正常的学生更爱用电子邮件而不是电话。所以,当我们考虑一个群体的需求是,我们实际上也带给所有学生方便,不管是聋人还是正常人。

为提供良好的医疗教育,预防疾病,学生是否可以获得教育资料和会议呢?教育资料是否被评定过并不断更新?医疗人员是否能使用电脑技术?大学生能否协助开发可视化的健康教育?聋人和正常学生会有不同,男性和女性学生会有不同的问题和需求。当然,学生在学校里的时候家庭和朋友的关系也会有所改变。

With the Deaf in the health care setting, we need to address communication. What can be done within the system to improve communication? Not just for the Deaf, but for all students. We know that having ramps instead of stairs helps those that need to use wheelchairs for mobility. We also know that ramps help mothers with young children in strollers, people with arthritis, and movers! Even students who can hear prefer to use email as opposed to the telephone. Therefore, when we think of access for one group, we are really providing access for all students, whether or not they can hear.

In order to provide excellent health education and prevent disease, are accessible educational materials and educational conferences available? Have materials been reevaluated and updated as necessary? Do health care staff have access to computer technology or university students who can assist in developing visually appropriate health education? There will be differences between the Deaf and the hard of hearing student. Male and female students will have different issues and needs. And of course, family and peer relationships will change while the student is in college.



# 交流

- •多种机会
  - •手语翻译
  - •实时字幕
  - •书面小册子
  - •有字幕或手语的录像
  - •电脑和电子邮件
  - •电话,传真和传呼机
  - •其他?
- •你好,我的名字叫Bob,这里是ABC新闻

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和聋人交流健康信息的方法有很多。人们用不同方式进行学习,有人通过听,看或者做来进行学习。当然手语翻译也是一种途径。如果你经常放一部影片给学生看,也许你下次可以加字幕,或中文字幕,或在有字幕的同时配手语翻译。图形手册很有帮助。文字过多插图很少的手册通常会被扔在一旁,聋人或者正常人都一样。图形便于眼睛观察,能够清楚的表达一个概念。计算机也给残疾人带来很大帮助。电子邮件和即时信息和电话一样可以传递信息。传真和文字传呼也适合于聋人交流。有没有其他方法?

There are many ways to communicate health information to the Deaf. Remember, people learn in different ways. Some learn by listening, some by seeing, others by doing. Certainly sign language interpreters are an option. However, if you have a video that you frequently show students, perhaps another way is to have it "subtitled" or captioned in Chinese, or have it "subtitled" and interpreted simultaneously. Graphic brochures are helpful as well. Brochures that are wordy with few pictures are often thrown out...not only by those who can't read, but also by those who can read! Graphics are easy on the eyes and help illustrate your concept clearly. Computer technology has liberated many with disabilities. Email and instant messaging can convey a message similar to the way a telephone answering machine takes a message. Fax machines and text pagers are another viable way to communicate with the Deaf. Are there other methods?

### 了解系统

- •学生卫生健康中心
- •心理健康中心
- •保密性问题
- •知识评估
- •紧急事件或紧急照看
- •再评估和修改

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也许学校里已经有一套健康系统了。但是是否对所有人开放?让我们举个急诊室的例子:有个学生星期六晚上11点头痛,发烧,喉咙痛。这个聋人学生知道医疗中心有开门吗?在那个事件有什么服务?他要打电话,叫校警,还是请人帮忙?如果医疗中心没开门,他要打急救电话吗?如何找到急救电话和急救室?附近有药房吗?他怎么打电话回家呢?如何使他尽量独立,而又能保密呢?

如果学生很压抑,或和伙伴吵架怎么办?学生有医疗保险吗?校外就医保险可以报销吗?医生知道手语吗?需要翻译吗?有"精神医疗室"吗?它是学校医疗中心的一部分吗?这种方式比较好,学生不会被人知道去"心理医疗室"。保密性是很重要的。

入学时候有介绍学校的医疗保健系统吗?有没有同学可以咨询?火灾或者地震紧急情况如何通知聋人学生?在美国,紧急情况会有闪烁报警系统通知聋人学生。有些学校有文字传呼报警。有些大楼会有电视显示报警信息。那么如何利用校外的医疗系统呢?急救室?他们有翻译吗?

你们应该不断的重新评定修改程序。如果遇到问题,残疾学生通常都会知道去哪里找资源。根据以往的经验,他们知道怎样解决。不要害怕问问题。聋人学生很乐意帮助你们出谋划策,完善系统。

Perhaps there is already a University Health system in place for all students. Will the entire system be accessible to all? Let's walk through a typical emergency--a student develops a headache with a sore throat and fever at 11:00 Saturday night. Does the Deaf student know when the health center is open? What are the options at that hour? Will he have to use the phone or can he get campus security or another person to help? What if the health center is open? closed? Does he have to call another emergency number? How will he get to an emergency room or an urgent care center? Is there a pharmacy nearby? Is there a way he can call home? What technology is available to make the student as independent as possible and ensure confidentiality?

What if a student is Depressed or just broke up with a partner? What are the options available? Will the student have insurance? Will insurance cover off campus therapists? Are there therapists who know sign language, or will an interpreter be needed? Will there be an obvious "Mental Health" Office, or will it be part of the "Student Health Center"? This option may be a nice one, since the student might not go to a place "known" to be the Mental Health Center. Confidentiality is a concern.

Is there orientation before school starts to explain the University health care system to students? Will there be peer educators? How will the deaf student be notified of an emergency such as a Fire or earthquake? In the US, we have flashing alarm systems that alert Deaf students to an emergency. Some have text pagers that go off when an emergency occurs on campus. Some buildings may have TV screens that continually scroll written announcements and emergencies. What about utilizing off campus health care services? Urgent care or Emergency rooms? Will there be interpreters available or access provided?

You will need to continually reassess and revise these procedures based on your experiences. If you have questions or concerns, often the disabled student knows the available resources. They know what has been successful for them and others. Don't be afraid to ask for help. The Deaf student will be happy to help you with ideas and resources to make your system the best it can be.



# 总结

- •个人经验
- •中国和美国存在的不同
  - •男女角色
  - •其他?
- •聋人教育
- •交流
- •知识和文化教育的经费

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总的来说,我已经给你们介绍了我的个人经历以及美国聋人和听力障碍人士的情况。 我还讲了美国现有的一些技巧和服务。当然,中国和美国存在文化和语言的不同。我们要考虑教育的不同,男性和女性角色的不同。还有其他方面吗?我们应该了解中国聋人教育和医疗保健的困难在哪里。知道困难后就可以用我们的知识去解决。我们可以提高中国聋人的教育水平,以及医疗的普及性。

我还介绍了在美国交流的重要性,和交流的困难在哪里。我提供的几种交流方式可以应用到大学的环境里。

你们现在知道大学里学生们健康保健知识水平会有不同。了解这些信息和他们的文化水平以后,你们可以准备相应的教育材料来进行改善。

In summary, I have given you my personal story as well as experiences of the Deaf and Hard of Hearing in the US. I have also given you some techniques and services that we have provided in the US. Obviously, there are cultural and language differences between the US and China. Certainly we need to consider educational differences as well as male and female role differences. Are there others? We need to know what the barriers are to education and health care of the Deaf in China. Once we know the barriers, we can apply this knowledge to create solutions. We can improve the educational system as well as improve access to health care for the Deaf in China.

I discussed the importance of adequate communication as well as barriers to communication in the US. I also provided several ideas and communication methods that you can use in the University environment.

You now know that health care knowledge may differ among the many students at the University. Once you have this information as well as their literacy level, you can prepare educational materials to address the appropriate issues.



# 总结

- •高等教育的问题和健康保健
- •预防于未来

大学系统对新学生来说可能会觉得太多甚至很不清楚,更不用说聋人学生了。知识是很有用的。我们提供的信息越多,学生就会越成功。我解释了大学之前聋人接受的文化和学校教育对他们在大学里的健康都会有影响。 我还解释了如果你的医疗系统很开放,就会更容易进行修改。问问学生需要什么,脑力激荡来产生解决措施。

残疾人的前景是光明的。我们在不断的发展新的教育和医疗技术,受益所有人。如果我们教育聋人和其他残疾人, 所有人都受益。很多时候残疾人都可以照顾好自己。他们让我们认识到我们考虑不到的问题,思想和可能性。浪费 脑力思维是很可怕的事。

The University system can be overwhelming and confusing to a new student, let alone a Deaf student. Knowledge is a powerful thing; the more information we can provide, the more successful the student will become. I showed you that Deaf culture and school education prior to college impacts their health while in the University setting. I also showed you that if your health care system is accessible to all, then it will be easy to modify if needed. Ask students what is needed and brainstorm for solutions.

The future is bright for people with disabilities. We continue to develop new educational and health care technologies that benefit all. If we educate the Deaf and others with disabilities, everyone wins. Often, the disabled take care of their own. They enlighten us with questions, ideas and possibilities that never occur to the able bodied. A mind is truly a terrible thing to waste.



问题?

谢谢!

Questions?

Thank you!