

Consumer Perspectives:

Creating a Brochure for Families of Children with Special Health Care Needs in Your Community's Immigrant and Underserved Populations

This information is based on the experience of the Massachusetts Consortium for Children with Special Health Care Needs in developing the brochure ***Is Your Child Different?*** with significant input from a consumer advisory group. Every element of the brochure – from key messages to color palette – was chosen based on what our consumer advisors told us. While the end result is a brochure tailored to families in Massachusetts, the model could easily be adapted for other communities nationwide. To share what we learned and facilitate the replication of ***Is Your Child Different?***, we offer this summary of the ideas and suggestions that shaped the original.

Our consumer advisory group reflected the brochure's target audience: it comprised parents of children with special needs from diverse immigrant and other minority populations. Advisors included members of the Eritrean, Vietnamese, Haitian, Chinese, and African-American communities. We purposefully recruited some parents of younger children, as the newness of their experience with the health care system could speak more directly to the experience of those families recently arrived in the U.S. The purpose of the advisory group was twofold:

1. To identify the persons, organizations and services most helpful to families of minority communities in accessing services for their children with special health care needs; and
2. To identify print communication strategies that appropriately reflect the cultural and linguistic needs and perspectives of this population.

Advisors were told that the goal of the project was to “help parents help their children who have special needs,” but the format, content, key messages and design would depend upon their recommendations.

Key Message

If they could offer only one piece of advice to parents trying to navigate the health care system on behalf of their children, our consumer advisors would say this: **Talk to other parents – they are your best sources of information.** Parents who are experienced with the service system are more helpful than many professionals, and those whose children have similar health needs are most helpful of all. Language barriers aside, connecting with parents who share linguistic and cultural backgrounds is not as important as connecting with those whose children have similar health needs.

Layout and Design

Our consumer advisors selected the **8.5” x 11” tri-fold brochure** format rather than a poster, flyer or postcard, saying it was small enough to tuck into a purse or pocket, yet not so small that it would be easily lost. (Refrigerator magnets were also suggested, but ultimately rejected as too small.) They recommended **bright, primary colors**, plentiful **photographs**, and a lot of **white space**. Too much dense text is especially unappealing for populations for whom reading is not the primary way of receiving information (in contrast to the radio, for example). White space also gives parents a place to jot down notes.

Family Resource Information

Our advisors thought it best to include information about **only one family support program** or organization so as not to overwhelm parents and discourage them from reaching out for help at all. (Consortium staff suggested Family TIES of Massachusetts, which is staffed by parents of children with special health care needs, provides family-to-family support, and is able to provide services in languages other than English; Family TIES approved the brochure before publication. Parent support groups and advocacy groups would also be good candidates.) Because our advisors stressed the importance of parents actually speaking to another parent, the brochure encourages readers to **make a phone call, rather than visit a web site**. Our advisors pointed out that referral to the Family TIES web site would not only assume a certain level of computer literacy and access, it would also have had less helpful outcomes.

Additional Messages

Calling a stranger to talk about your child’s problems – in what may or may not be your native language – can be intimidating for a number of reasons. Our brochure tries to:

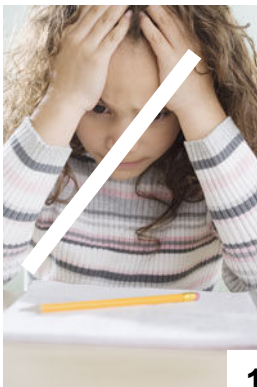
- acknowledge that **it’s difficult to ask for help**
- encourage parents to **do it anyway**
- assure them that they **don’t need to know exactly what to ask**
- offer a suggestion of **what they might say**; and
- reassure parents that their **privacy will be respected** and their conversation kept confidential.

Wording and Language

The Consortium's task was to prepare an **English-language version** of the brochure. (The Opening Doors Project, for which the brochure was developed, has also set the goal of working with community organizations to translate it into **other languages**.) A key recommendation from the advisory group was to **keep the wording simple**. The majority didn't like the English term "special needs," as it can have negative connotations for some parents and be meaningless to others, especially those whose children don't yet have a diagnosis. They wanted to **replace "special needs" with another word or phrase** – one that would have a similarly broad definition but also be meaningful in other languages. Our consumer advisors came up with the word "different," then suggested using it to form a question rather than a declarative statement, which might sound negative. The discussion led to a full consensus on the brochure's cover statement, "Is Your Child Different?"

Photographs

Our consumer advisors elected to use photos of **children from diverse population groups** for the English-language brochure. They noted that groups producing the brochure in their own language might want to use photos reflecting their own community – perhaps even **photos of their own children** – or, in some cases, not use photos of children at all. The group reviewed and approved of sample stock photos obtained by Consortium staff. Photos 1 and 2 below were particularly well received. Both convey a feeling of shame, of a need to hide, of anxiety, and these are emotions to which the group felt many families could easily relate, and ones that are important to acknowledge. The photos were purchased from an online **stock photography** vendor. Whether photos are purchased online or contributed by families themselves, it is essential to secure proper usage rights or consent forms.



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Logos

Some concern was expressed about the use of official logos or other ways of conveying or implying that the brochure is a “product of the government.” Because some immigrant populations come to the U.S. with a suspicion of what governments can, or cannot, do for families, our parent advisors felt it best to play down any graphics or content that implied a government or “official” imprint. For these reasons, no logos appear in our brochure. Organizations that collaborated on the project are listed by name only.

Cultural Factors

Consideration of cultural factors was part of our discussion of many aspects of the brochure, including wording, layout, and photography. One early idea for the layout was rejected, for example, when our advisors told us that “Haitians don’t really use thought bubbles,” like those in cartoons, to communicate. Perhaps the most pervasive cultural factor we discussed was that of **secrecy and shame associated with having a child with a disability or other special need**. Advisors from the Eritrean, Haitian, and Chinese communities in particular noted how parents may deny there is a problem or avoid reaching out for help; for tentative parents, help from someone over the phone may be more comfortable than a face-to-face meeting. All agreed that a single brochure could not be expected to overcome a deeply rooted cultural barrier, but that it might help tip some reluctant parents in the direction of asking for help, or help one parent convince a spouse to agree to do so.

Dissemination

Doctors’ offices were recommended as a good outlet for disseminating the brochure, as all parents share the experience of taking their children to the doctor. Some parents thought it would be best for it to be in the exam room, or for the doctor to hand it to the parent; they noted that there is already a lot of literature in most waiting rooms, and that they might be embarrassed to pick it up in front of other people. Other suggested venues for dissemination were **schools, embassies and consulates** where people go for help with immigration paperwork, and **community-based organizations**.

The ***Is Your Child Different?*** brochure is available at www.massconsortium.com. It was produced through Opening Doors for Children & Youth with Disabilities and Special Health Care Needs, a collaboration among parents from communities in the Greater Boston area and the Institute for Community Inclusion at the University of Massachusetts Boston and Children’s Hospital Boston.