

Adopting the International Child with Special Needs

Over 30 years of evaluating special needs children gives author, Teri Bell, a special insight into what parents need to be aware of.

October 01,2011 / Teri Bell

Over the years, families considering the adoption of children with special needs have asked me a multitude of questions. If you are considering the adoption of a child with special needs, I am sure that you have many questions you would like answered. Sadly, in the thirty plus years of working directly with children with special needs and their families, I've learned that no absolutes exist when looking for answers regarding the adoption of this population of children. I found the answers to be as variable as the families and children involved. I began to realize however, that there are guidelines to help families make decisions regarding the addition of a 'special' child to their family. The guidelines tend to differ, however, depending upon the adoption program being considered. The medical expertise available, the medical facilities used, cultural understandings, capabilities of the each overseas agency and the expertise of the US agency which is representing the family overseas, all differ greatly from program to program. Each of these variables contribute to how questions are answered and what the realistic expectations for that program should be. In the following pages, I have attempted to lay out for you, the potential adoptive parent(s), some issues to reflect upon and guidelines you may find useful.



In updating this article I realize now that the original article did not address the fact that families come to the adoption of a child with special needs in different ways. Some of you know from the time you make the decision to begin an adoption that you wish to adopt a child with special needs. You may even have defined the specific medical issue or issues you feel you most comfortable incorporating into your lives and you may actually seek either an agency or a child who fits that criteria.

Families other than those mentioned above, may have come to adoption with the intention of adopting a child who has not been identified as having any specific medical or developmental diagnoses. As you have informed yourselves regarding adoption or seen or read waiting child listings, you may have found yourselves drawn to a specific child who is waiting. When this happens, your mind set regarding the direction of your adoption may need to be revised. When this happens there is a great deal of "catch-up" that needs to be accomplished in a short period of time. Your home study may need to be revised reflecting your openness to the adoption of a child with special needs. Before this can be accomplished however, you may need to convince your social worker that this change of plans is the right one for your family. For those of you who are in this situation, I suggest that you carefully evaluate the impact this can have on your entire family and revisit the expectations you had set out originally for yourself/yourselves. Look at why you made your original plan to adopt a child without medical issues and look at the fears or concerns that encompassed that decision. Then look at the possible joys and advantages that the adoption of this child could bring your family. Weigh your decision carefully as the adoption of a 'special' child can change your life in ways you can't imagine. IF going forward is the right

decision for you and your family and the child you are considering, all involved can benefit in so many ways.

Choosing An Agency and a Program

The first major step for those of you setting out on the path of adopting a 'special' child is to learn as much as possible about the US agency which will represent you overseas. This may or may not be the same agency which is performing your adoption study. When choosing your US 'international' agency, be prepared to ask informed questions about their international programs in general. Here are a few suggestions:

q What is the scope and type of information (e.g. birth history, medical concerns, medical treatment, medical/developmental test results) which you can expect to be made available to you? See section on child referral information.

q Who is representing you and the child in the child's country of birth?

q How long has this program been established?

q How many children have been placed from this program?

q Is the agency willing to put you in contact with other families who have had placements from this program? (It is important that you have several families to talk to before, during and after your placement.)

q Is your agency willing to help you locate adoptive parent groups and/or contacts in your area so that you can access adoption support and current information?

q Can your agency help you find resources in your area regarding parenting of children with special needs?

q Will your agency be there for you after your child comes home?

Adopting children with special needs requires more specific information whenever possible:

q Does the overseas agency have the ability to obtain more information if you or your medical doctor requests it?

q Is the agency receptive to asking questions of their representative on your behalf?

q Does the program you are interested in have a history of getting requested information in a reasonable time period?

q Who does the agency representative, or the international agency, consult with overseas regarding the children with special needs, and what are their qualifications?

q What experience does the person identifying the children have in special needs adoption?

There is no perfect program. In asking these questions you are really looking to find out the parameters of the programs you are considering. Once you know the limitations or advantages of the programs you are considering you can make a more responsible decision.

Referral Information

Adoptive families often wonder how much information they should expect in a referral of a child overseas. As child care standards and medical care differ significantly from, country to country and often from program to program within the same country, each program has its own limitations as to the information they provide. Therefore, it is impossible to say what should constitute a realistic expectation. You should assess the standard referral information provided by the program you are considering and if you are comfortable with what you learn, this program may be a good option for you. Again, I suggest that you talk to other families, whenever possible, who have adopted through this program. In talking with these families, ask about the information they received, how accurate it turned out to be and whether they would, with a similar amount of information, proceed with another adoption from the same source referral if they chose to adopt again. While their decision may not be your decision, it will give you a better basis for making your own.

Ideally, of course, you would hope to have most of the following information on your infant referral:

q date of birth

q birth weight

q periodic measurements

q gestation of birth

q delivery information

q head circumference at birth and at present

q present health

q any available birth and family history

q periodic physical, social and developmental information

q history of alcohol or other chemical use in birth family, if known

q vaccination history

Unfortunately, with some programs not all of this information is available. If you feel that some of the above information **MUST** be included in your referral for you to proceed with a placement from overseas, it will be necessary for you to ask your agency if your chosen program includes or could obtain that information.

Information on an older child ideally would include:

q Any of the information you would want on an infant (Often, however, this information has not been gathered or has not been passed on to the child's most recent caretaker or facility).

q The child's developmental appropriateness. Depending on the child's age, that would mean questions such as: Is the child walking, talking, able to answer questions, able to read, able to carry on a conversation or any other age-appropriate developmental expectations.

q If the child is presently in school, it would be important to receive as much information as possible regarding how they are functioning in the classroom and how they are functioning in relation to their classmates.

o Is the child motivated?

o Does he/she try to succeed? How do they deal with frustration/disappointment?

o Is the child in an age appropriate classroom setting? If not, why not?

q What is the child's attitude towards adoption?

q Does the child understand the concept of adoption and, if so, is the child interested in having adoption be part of his/her life?

q Are there significant background issues that should be known by their new family and is the child aware of these issues?

q Does the child have a memory of their birth family?

q Was the child relinquished or abandoned?

q Does the child have a history of any emotional bonding?

q Is there any known sexual or physical abuse in the child's background?

q What does the child know about his/her past?

q Is the child able to discuss his/her past?

q How many moves has the child experiences?

- q How has the child handled their past moves?
- q How many major losses has the child experienced?
- q Has the child developed bonds with one or more adults?
- q Has the child developed friendship with his/her peers?

Again, I stress that both for infant and older child referrals, you would be fortunate to receive all of the information above, in a majority of the overseas adoption programs.

Seeking Information and Community Information

It is expected that all families who are entering into the adoption of international children with special needs have looked at the financial, educational, and insurance aspects of their adoption. Without having each of these areas reconciled before looking at a referral of a child, you are only asking for heartache and frustration. You should know specifically the conditions of your insurance coverage. Does your insurance cover pre-existing conditions of adopted children? Does it cover children from the moment they leave their country of birth? Federal laws state that children placed into a family for the purpose of adoption will be covered from the time of arrival into that family and that pre-existing conditions will be part of that coverage. Some state laws have overridden the federal law and certain employment situations are exempt from this law. This should be researched thoroughly before you proceed.

Once you have received a referral of a child from your agency, I feel that it is imperative that this referral be discussed with others as you make a final decision. At this point there are many options open to you. You may wish to contact any or all of the following to help you gather the information you need to make your decision.

There is a great deal of information available on medical and developmental issues. In many instances you can find resources as to how these may relate to adoption. Be sure to ask your agency to suggest literature and/or organizations which can be of help to you. On the web you can find many books at <http://www.celebratechild.com>

If you are adopting a child who has lived for a period of time in an institution (this could include long term hospitalization) it is imperative that you inform yourself about the issues of attachment, bonding and institutionalization. For great information on the adoption of older children, try the RainbowKids Older Child area at: <http://www.rainbowkids.com/olderchild/index.html> or try <http://www.olderchildadoption.com/>. I cannot stress enough the importance of informing yourself about adoption issues.

The first thing you will probably think of doing, is taking your referral to a doctor that you trust. Another excellent option is to contact one of the International Adoption Clinic or doctors. Some cities have set up international adoption medical clinics which will not only

evaluate the children who are entering or have arrived into their own community, but will also be open and available to phone calls and consultations from families or physicians, country-wide. If you wish to know how to contact these clinics, you can ask your agency, your physician, your local adoption support for references. Here is a site that lists the adoption doctors around the country: <http://www.welcomegarden.com/medical.htm>

I have found, that even with the trusted family doctor, families can be frustrated and overwhelmed by their initial contacts with the medical community. It is often difficult for families to know what questions to ask once they meet with their doctor. Families who have the most success in this area are families who have prepared ahead of time and have done their homework regarding the information they have received on the child's referral. If the child, who has been referred, has a specific handicapping condition, I suggest that you do an internet search on the specific medical issue, visit your local library. Contact with the appropriate local organization(s), to inform yourself regarding the resources in your community for children with this medical issue will also help you gain necessary information. The information you accumulate within the first few days of doing this "homework" may be startling. While doing all this research, remember, that there are varying degrees of severity regarding most diagnoses. What is encompassed under one label can range from mild to severe and, before panic sets in, a clear picture of where the child you are considering fits in that continuum is important. This time spent information gathering, will better prepare you to discuss the child's prognosis with your doctor as she/he explains how the diagnosis affects this particular child.

Involvement with parent groups that meet to discuss the concerns of children similar to the child whose referral you are considering can be helpful to you as you try to put the medical information into perspective. The following organizations can lead you in the right direction.

q Department of Health and Human Services at <http://www.hhs.gov/> 1-800- 358-9295

q National Institutes of Health at <http://www.nih.gov/icd/>

q National Health Information Center
at: <http://www.health.gov/nhic/> or <http://www.health.gov/nhic/pubs/tollfree.htm> 1-800 336-4797

On these sites you can find the number for the national organization specific to your needs and the national organization can put you in contact with your local chapter.

Talking to Other Parents:

Other parents can be one of your greatest resources. Parents both by birth and by adoption are able to offer their support in a non-threatening environment. In these conversations, you will be receiving a great deal of new information at an emotional time. You will be able to begin to understand the day to day lives of parent who are parenting children similar to the child you are considering. Obviously, no two children or situations are the same but the information you learn can be helpful. Please reflect upon what you have heard and learned before you make any final decisions.

Don't be surprised if, at first, it is easier for you to ask questions and express fears with people who have experienced your concerns, than it is with your social worker. After once expressing your thoughts with other parents, however, you will probably feel more comfortable expressing your thoughts with your worker. Remember, your worker wants you to make the right decision for your family and for the child you are considering.

Medical Consultations

There are many questions that the doctor may want to ask you, and there are many questions you will wish to ask of the doctor you are consulting. Before you begin the consultation, I feel that it is imperative that from the outset you make it clear to your doctor that you have already made the decision to proceed with an international adoption and that you have already made the decision to accept the referral of a child with special needs. You need to explain that what you want from this consultation is the information and guidance she/he would give to any family who entered the office, asking the same types of questions regarding their child by birth. Explain to the doctor you understand that she/he is not making the decision for you; she/he is only helping you to become better informed. Explain that you are not asking whether or not you should proceed with the adoption.

You may find that as you talk to a variety of medical people, you will come to realize that diverse philosophies and treatments for the same condition in the same community can exist. Before making your final decision, it is important for you to take all of the information you have received from the specialists and decide how much, if any, of this information contains adoption bias by the doctor who was answering your questions. Physicians can hold the same prejudices against international adoption and children with special needs that others in the community hold. International adoption is NOT without controversy. **REMEMBER, THE DECISION TO PROCEED OR NOT TO PROCEED WITH A CHILD REFERRAL IS A DECISION ONLY YOU AND YOUR FAMILY CAN MAKE.**

Many people are angry or frustrated when the doctor they consult does not give them definitive answers. Please understand that the medical doctor who is giving information on a child from another country is put in a precarious position. First of all, the doctor you are consulting obviously has not made the original diagnosis, and is being asked to give opinions on someone else's expertise. This doctor does not usually know specifically how this child was diagnosed, what tests were given to reach the diagnosis, what equipment was used for these tests, whether the x-rays, EKG's, echoes, sonograms, or EEG's were interpreted accurately, whether the blood chemistry was examined accurately, and whether there are genetic or chromosomal factors which may play a part in this child's diagnosis. Furthermore, your consulting physician may not be able to determine who specifically diagnosed this child, if that person was a specialist in the area of this child's particular medical concerns, how accurate the original physician's previous diagnoses of this type have been or if the diagnosis has lost something in the translation from their language to English. Certainly, this all explains that there are hazards to interpretations of test results or readings by another doctor. As a result your consulting doctor is likely to qualify her/his statements regarding this child and the child's present and future situation.

The question of seeking a second opinion is often raised by families who are adopting children with special needs. It is my opinion that, if you are considering adding a child with a medical concern, you should check with more than one physician. Medicine is not an exact science and there are usually many differing opinions on any one issue, especially when that issue is seen infrequently in the United States. I suggest, that if you are not consulting one of the international adoption doctors, you ask the physician you are consulting, if they have had professional experience with children from other countries or cultures. I would also suggest that you ask if this diagnosis is common or uncommon to this child's country of birth. There are many reasons for families to seek second or even third opinions from the medical community. Often, the family doctor you contact is only able to provide you with a broad outline of the specific medical concern you are interested in. That doctor may refer you to a specialist in this particular child's disability. At other times, members of the community, parent group members, or other adoptive parents may suggest a doctor that they found to be extremely helpful. Some families even seek a second opinion when they feel the need to have a positive first opinion corroborated. I have also encountered families who, although they have received quite negative evaluations, feel that no matter what they hear, the referral they are now holding is information on "their" child. These families seek second opinions to find a medical provider in their community who they feel can provide their future child with the best available treatment.

Requests for Additional Information

Frequently, the medical personnel consulted request further information regarding the child's medical condition. In some programs, this would just not be possible and in those instances you will need to make a final decision with the information you already have. Often, the tests or information which have been requested are either not within the capabilities of the medical or social work staff of the country where the child is presently living, or test facilities and/or equipment are unavailable. It is also possible that the overseas organization is unable to afford to supply expensive intricate testing. You will need to ask the advice of your agency as to whether the information requested is appropriate and realistic for your particular program. It is your right to request any and all information you feel you may need in order to make a decision regarding a particular referral. It is the agency's responsibility to be knowledgeable regarding the international agency's attitudes towards requests for more medical information. You and your agency must be aware of the sensitivities of the country from which the referral was sent, and how this request will be received.

Requests for information will lead to delays and everyone involved needs to discuss and decide why the information you are requesting is important to you. You, your social worker, and your physician need to carefully scrutinize the information being requested. Why is this information needed? Is the information being requested to aid in treatment upon arrival or is it being requested in order that an adoption decision may be made? Questions you need to ask of yourself regarding your request are:

q What are you going to do with the information when and if you get it?

q How will it make a difference to your decision regarding this particular child?

q Can you set a time limit where, if no information is received, you will make a decision without it?

q Can you decide beforehand, what your decision will be if given positive or negative information, or if no new information is received?.

It is important to remember that time is of the essence when considering the referral of a child. While you need to gather as much information as possible in order to make an informed and caring decision, at some point, it is also important to remember that, as long as you hold this child's information, that child remains a waiting child. The children with special needs in other countries have often waited too long already. Even if you cannot handle, and are not ready to accept, the medical concerns of the child being referred, this child may be perfect for another family. This is not to say that the request for additional information is inappropriate. In many cases, this information is not only appropriate, but is often appreciated by the overseas agency who will have an opportunity to learn more about this child and other children with similar medical concerns. At the same time, indecision might hold up or take away an opportunity for the child's placement or referral to another family, so when you make that request, do so, with serious intent on proceeding.

Decision Making

Can you truthfully say that you have looked at all your concerns objectively? You may still be concerned about some issues, but do you feel deep down that the decision you are making is the right decision for you and your family? This is the time to question your choice. Can you live with the ongoing hours of care this child will need? Are you proceeding because you pity the child? If pity is involved, can you overcome it?

If the unanswered questions at this point are extremely disturbing, this may not be the right child for you. It is wonderful to believe that the child who has not thrived in his or her homeland will respond to your love and attention. This has proved to be true in many cases, but not all of them. Realistic expectations are a must, because unfortunately, LOVE DOES NOT CONQUER ALL!!!

A failure-to-thrive or institutionalized child, a developmentally delayed child, or a child with a parental history of substance abuse, physical or sexual abuse, may not respond, catch up and accomplish the dreams you have envisioned. That child may always remain delayed or unstable. There are many children and families in the United States who have always received love and yet never measure up to America's mainstream. This is a fact that needs to be part of your decision. So many people can spend long hours, days or months working with a child when they feel the outcome will be a positive one. Can you still feel that child is a part of you, if the outcome is not as positive as you had hoped?

These problems do not only apply to the non-thriving infant or young child. Some of the older children who are placed for adoption are not and can never be like most of their peers. There has been a great deal written about the child from another culture, but have you thought about the far-reaching aspects this can have for you personally? The attitudes, feelings and outlook

on life we take for granted can often be totally and literally foreign to a new child for many years to come. If you are bringing an older, handicapped child into your home, you may be surprised that your child looks down upon other handicapped people. In some cultures, differences are not acceptable to the majority. These children, despite their own physical conditions, are often products of those feelings. This may also be an indication of how they feel about their own self-worth. Patience and understanding are crucial in such situations.

A wonderful aid in decision making, is to spend some time with children who have similar physical challenges to the child you have on referral. Visit the child at their home or school, if possible. If you see no problem accepting what you observe at this point, project some of your fantasies to the teen years, or visit with a teen and their parents. Are you still comfortable? All of us have images of ourselves that we hope are true. We look at children and families that have "made it" and we say we can do that too. We want to see ourselves as strong enough and capable enough to endure whatever challenges life presents. Be sure that you are being realistic regarding your strengths and weaknesses.

We also, have expectations and fantasies for our children. Unfortunately, these expectations can rarely be fulfilled. The reality of the situation becomes all too clear after the fact, so it's best to examine ourselves beforehand whenever possible. There are no guarantees in life as to the future of any child, whether that child is brought into the family by adoption or by birth. You must feel comfortable proceeding with your adoption plans. It is imperative that you remember that adoption, like birth, is a lifetime commitment.

Using the information available to you, you need to look at the best and worst scenarios. Whether this information is complete or whether it is limited, you must consider how the information differs from what you expected or hoped to receive. You must then decide if you are comfortable with the information you have received, and whether given the worst scenario, you feel strong enough to be able to cope with whatever is ahead of you.

While You Wait

The waiting can be excruciating. Take this waiting time to contact the International Adoption Clinics, find out what they suggest as far as initial medical and follow-up visits and be ready with this information when you take your child to his/her initial medical check with your chosen medical provider.

You will also need to look into the special education and early childhood special education programs available in your area. Many children who have been institutionalized have benefited by Sensory Integrations Therapy. You may wish to check out your options for this type of therapy in your area. Here is a site that might be helpful regarding Sensory Integration: http://www.comeunity.com/disability/sensory_integration/resources.html.

As you consider medical interventions, you need to know how soon after arrival your child will be covered by the educational system and if these programs will be adequate for your child. I suggest that, if you know that the child you are considering will need special educational services, that this is the time you contact the program's director and make an

appointment to visit the school or center where the program is held. You may also be entitled to in-home services and that too should be investigated. It is important to know your rights under the law for services provided to your child, if such services are necessary. You need to know the facilities available and the proximity of these facilities to your home. Will busing be provided for the child? Will services for the school aged child be provided within the regular school setting? Each family has the obligation to seek out answers and ask any questions which might make your lives and the life of the child you are adopting more comfortable and less stressful.

Summary

I have worked with well over 1000 children with special needs and their adoptive families during my career. I have occasionally seen families experience heartache, disruption and divorce. Some of these families feel that the major stress in their lives began with the addition of their child with special needs. The majority of families however, feel that the addition of their child with special needs was one of the greatest experiences of their lives. Much of what I have written here may appear to be disheartening and pessimistic. I truly don't mean it to be that. The point I am trying to get across, more than any other, is that adding a child with special needs to your family requires realistic and objective decision making. **THIS DECISION MUST BE MADE WITH ALL FAMILY MEMBERS BEING ON THE SAME PAGE AND EQUALLY INVESTED IN THIS ADOPTION.** There is no parenting that is easy and without problems. There are few families who don't experience doubt and fears as they proceed through the process. The addition of a child with special needs can enhance the difficulties and the problems faced in parenting, but done correctly, it can also be a joyous experience. **AN INFORMED DECISION CAN MAKE THE DIFFICULT TIMES EASIER TO MANAGE AND BE THE MOST REWARDING AND FULFILLING DECISION IN THE LIVES OF BOTH YOU AND YOUR NEW CHILD.**

Thoughts or comments on this article are welcomed.

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