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Abstract

Note about language: This article was written in 1977 and as such uses language such as "he" and "him" as generic terms for children, professionals and parents.

This article is written by a parent who feels she is one of a "lost generation of parents" who feel intimidated by or angry with professionals. This is because of past experiences, current dilemmas and mixed messages. The author gives reasons and examples, and goes on to provide some suggestions that could be helpful to the parent, the professional, and therefore the child. She says that changing habits of communication cannot happen without the efforts of both parents and professionals. **Keywords: Families, Professionals**

A lost generation of parents

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Beckie, the fifth of my five children, is profoundly retarded. The 13 years since she was born have been enlightening ones for me. I have learned enough about other parents and their experiences with professionals, about parent organizations, and about the service system for "exceptional" children to be able to pass as a professional myself and get paid for doing what I used to do as a volunteer. Although I have learned much, I am clearly one of the lost generation of parents of handicapped children. We are parents who are either intimidated by professionals or angry with them, or both; parents who are unreasonably awed by them; parents who intuitively know that we know our children better than the experts of any discipline and yet we persistently assume that the professionals know best; parents who carry so much attitudinal and emotional baggage around with us that we are unable to engage in any real dialogue with professionals - teachers, principals, physicians, or psychologists - about our children.

Between birth and the age of 13 Beckie has seen 11 physicians representing 5 specialties. She has also been referred to an audiologist, an occupational therapist, an optometrist, physical therapists, psychologists, and speech pathologists. In answer to the common accusation that parents "shop" for professionals who will give them a less painful diagnosis, I would suggest that most, like myself, see large numbers of professionals because the complexity or severity of the child's condition requires periodic re-evaluation from a variety of viewpoints. One-stop diagnostic centres did not exist when our children were growing up; few exist now, so we have been "referred" from one diagnostician to another.

THE CLOSED FILES

Seeing so many diagnosticians and evaluators presents a problem. Not many parents are fortunate enough to have a paediatrician or family physician who will co ordinate all the information for them. People move and change doctors. Some doctors are unwilling to be co-ordinators in the first place. What happens to the reports? They are collected in manila folders that follow the child from clinic to clinic and school to school. This would be fine if one master folder containing copies of all the information were in the hands of the parents. However, few parents are given copies of these reports. Strangers are permitted to read the contents of the child's records; the parents generally are not.

When we parents fill out the application forms for a school, we sign a release form which says that the school may collect information about our child from past diagnosticians and schools. We usually do not ask to see the information which is being collected or sent. But we sign our names and give access to people whom neither we, nor our children have met, who may read the records, mull over them, and make vital decisions about the education or treatment of our children on the basis of what they read.

Beckie has accumulated a thick folder in her 13 year pilgrimage from professional to professional. I have heard countless "interpretations" of its contents by social workers, but I have only read the accumulation once - last year. I did so then with feelings of guilt, because my access to them came as a professional on the staff of the organization which runs her training program, not as her parent. I found nothing in them that I could not understand, or ask someone about if I did not, and nothing that could not have been discussed freely and openly with the person who wrote it. And I suspect that my cause is typical rather than atypical. Sometimes the record collection process meant delays of 2 or 3 months before interviews for application to a school were granted. How much simpler it would have been if I had been able to carry her records with me.

THE IRONIES

Anyone who has lived with a handicapped child during the last decade or two will be able to construct a list of ironies that he has learned to live with. The following ones are derived from my Beckie notebook, as well as from talks with other parents.

1. The responsibility for monitoring our children's progress through the fragmented service system has been ours, but the array of physicians and other professionals we have seen have assumed that we could not possibly understand the complexities of their trade or that it would take too much of their time to explain them to us. We have had the responsibility, but educating and equipping us to do the job better was generally not considered a part of the diagnostic obligation.

2. A parent who thinks something is developmentally wrong with his child usually turns to a physician who has probably only had minimal exposure to the total needs of the handicapped child and his family. Physicians are notoriously unschooled about non-medical services and often cannot tell the parent what schools are available for handicapped children, or even if schools are available.

3. The more specialised the diagnostician is, the less concerned he is to give information to the parents and the less willing he is to deal with the parents' situation and feelings. Referral of the mother for counselling has been a common and comfortable solution for the physician or other diagnostician; but when parents are repeatedly forced to ignore many of their concerns, they are never free of them.

4. Some of us are told repeatedly by professionals that we should institutionalize our children, but we find institutions to be places that are the least equipped to help children.

5. We could release information about our children to professionals, but we have not been allowed to read it ourselves.

6. Now, we are often told that the best place for our children is in the community, in a neighbourhood, with his family or a substitute family. Yet there are not enough group homes to begin to meet this demand, and foster homes are equally hard to come by. That leaves, as before, our own homes with respite care and home support services, still only a possibility in most communities.

7. It is now commonly accepted that our children have a constitutional right to a free education, but extra appropriations to make the classrooms materialize have not yet followed the legislation and litigation. We are told again to inform our legislators of the need. Why must we tell them **again**?

8. In the past we were made to feel guilty when we did not institutionalize our children, and now, under the new normalization principle, we are made to feel guilty if we do.

THE EFFECTS

So much for the ironies of our past experiences and our current dilemmas. We have learned to live with them, but not without accumulating some scars which clearly mark us as members of the "lost generation":

- We are angry. We have gone to the helping professions and have received too little help.

- We are still in awe of specialists and intimidated by their expertise.

- We are unduly grateful to principals or school directors for merely accepting our children in their programs. The spectre of 24 hour a day, 7 day a week care at home, with the state institution as an alternative, has made us too humbly thankful.

- We demonstrate a certain indifference to the latest bandwagon on which the mental retardation experts are riding. Mixed messages have been so much a part of our history that, rather than join the parades, we tend to listen politely, then do what we think best for our child. We are often, therefore, accused of apathy.

- Many of us have concluded that it is best not to worry about next year (or tomorrow) because things might be better then (or worse). Certainly it seems impossible to "plan for the future" as most of us are so frequently admonished to do. Generally I have found that those who wanted me to plan for Beckie's future were suggesting that I place her on the roster for permanent residence in the state institution. That is, in fact, the only option available at present. In Maryland I cannot even provide for her future by putting money aside and setting up an inheritance. If I die, and she must enter an institution, the state's general fund becomes heir to her belongings, and the money saved could go for something as remote to her well being as highway construction. So we worry about the future, but planning for it is not yet really a fruitful activity.

- We are tired. We have kept our children at home and raised them ourselves, with all the extra demands on time and energy which that implies - often without much help from the community, neighbourhood, professionals, friends, or relatives, and in fact commonly against their well intentioned advice. We have founded parent groups and schools, run them ourselves, held fund raising events to pay teachers and keep our little special schools afloat, organized baby sitting groups, and summer play groups. We have built and repaired special playground equipment for our children's use at home and at school. We have painted classrooms and buildings; we have written legislators and educated them about our children's needs and rights. We have collated and stapled hundreds of newsletters, attended school board meetings, lobbied at the state legislature for better legislation for handicapped children, informed newspaper reporters about inhumane conditions in institutions, and written letters to editors. All this we have done for a decade or more.

Small wonder that so many professionals should often prefer not to deal with parents. Few of these qualities encourage the kind of open, frank, informative dialogue that the professional wants - possibly as much as the parent *should* want it.

Changing habits of communication cannot happen without efforts from both parents and professionals. Here are some suggestions for achieving the dialogue that could be so helpful to the parent, the professional, and most importantly, to the child.

SUGGESTIONS FOR PROFESSIONALS

- Let the parent be involved every step of the way. The dialogue established may be the most important thing you accomplish. If the parent's presence is an obstacle to testing because the child will not "co-operate" in his presence, the set up should include a complete review of the testing procedure with the parent. (Remote video viewing or one-windows are great if you are richly endowed.)

- Make a realistic management plan part of the assessment outcome. Give the parents suggestions for how to live with the problem on a day to day basis, considering the needs of the child, the capacities of the family, and the resources of the community. Let the parents know that you will suggest modifications if any aspect of the management plan does not work.

- Inform yourself about community resources. Give the parents advice on how to go about getting what they need. Steer them to the local parent organisation. Wherever possible, make the parent a team member in the actual diagnostic, treatment, or educational procedures. It will give you a chance to observe how the parent and child interact.

- Write your reports in clear and understandable language. Professional terminology is a useful shortcut for your own notes, and you can always use it to communicate with others of your discipline. But in situations involving the parent, it becomes an obstacle to understanding. Keep in mind that it is the parent who must live with the child, help him along, shop for services to meet his needs, support his ego, and give him guidance. You cannot be there to do it for him, so the parent must be as well informed as you can make him. Information that he does not understand is not useful to him. The goal is a parent who understands his child well enough to help him handle his problems.

- Give copies of the reports to parents. They will need them to digest and understand the information in them, to share the information with other people close to the child, and to avoid the weeks or months of record gathering which every application to a new program in the future will otherwise entail.

- Be sure the parent understands that there is no such thing as a one shot, final and unchanging diagnosis. Make sure he understands that whatever label you give his child (if a label must be given) is merely a device for communicating and one which may have all kinds of repercussions, many of them undesirable. Make sure he understands that it says very little about the child at present and even less about the child of the future. Caution him about using that label to explain his child's conditions to other people.

- Help the parent to think of life with the child in the same terms as life with his other children. It is an ongoing, problem solving process. Assure him that he is capable of the problem solving and that you will be there to help him with it.

- Be sure that the parent understands their child's abilities and assets as well as his disabilities and deficiencies. What the child can do is far more important than what he cannot do, and the parent's goal thereafter is to look for, anticipate, expect, and welcome new abilities and to welcome them with joy when they appear. Urge him to be honest with their child. Tell him that the most important job he has is to respect his child, as well as love him and to help him “feel good about himself”. Tell him that blame, either self blame or on the part of the child must be avoided.

- Warn the parent about service insufficiencies. Equip him with advice on how to make his way through the system of "helping" services. Warn him that they are not always helpful. Tell him that his child has a right to services. Tell him you insist on being a part of all decisions about his child.

- Explain to him that some people with whom he talks (teachers, doctors, professionals of any kind, or other parents) may emphasize the negative. Help train the parent not only to think positively but to teach the other people important in his child's life to do so.

SUGGESTIONS FOR PARENTS

- You are the primary helper, monitor, co-ordinator, observer, record keeper and decision maker for your child. Insist that you be treated as such. It is your right to understand your child's diagnoses and the reasons for treatment recommendations and for educational placement. No changes in his treatment or educational placement should take place without consultation with you.

- Your success in getting as well informed as you will need to be in order to monitor your child's progress depends on your ability to work with the people who work with your child. You may encounter resistance to the idea of being included in the various diagnostic and decision making processes. The way you handle that resistance is important. Your best tool is not anger. Some of your job will include the gentler art of persuasion. Stay confident and cool about your own abilities and intuitions. You know your child better than anyone else; you are a vital member of the team of experts.

- Try to find a person who can help you co-ordinate the various diagnostic visits and results. Pick the person with whom you have the best relationship, someone who understands your role as the principal monitor of your child's progress throughout life and who will help you become a good one.

- Learn to keep records. As soon as you know that you have a child with a problem, start a notebook. Make entries of names, addresses, phone numbers, dates of visits, the persons present during the visits, and as much of what was said as you can remember. Record the questions you asked and the answers you received. Record any recommendations made. Make records of phone calls too; include the dates, the purpose, and the result. It is best to make important requests by letter. Keep a copy for your notebook. Such documentation for every step of your efforts to get your child the service he needs can be the evidence which finally persuades a program director to give him what he needs. Without concise records of whom you spoke to, when you spoke to him, what he promised, and how long you waited between the request and the response, you will be handicapped. No one can be held accountable for conversations or meetings with persons whose names and titles you do not remember, on dates you cannot recall, or about topics which you cannot clearly discuss.

- Understand the terminology used by the professional. Ask him to translate his terms into lay language. Ask him to give examples of what he means. Do not leave his office until you are sure you understand what he has said so well that you can go to your child's teacher, for instance and explain it in clear, understandable language. Write down the professional terms too. Knowing them might be useful some time.

- Ask for copies of your child's records. Don't just try to remember what was said in conferences. Learn as much as you can about your child's problem by reading. Don't believe everything you read. Remember: Books are like people. They might present only one side of the story.

- Talk freely and openly with as many professionals as you can find. Talk with other parents. Join a parent organization. By talking with people who "have been through it already", you can gain a perspective on your particular problems. You will also receive moral support and will not feel quite so alone. Get information from parent organizations about available services and about their quality. Remember that a particular program might not help your child even though it has proved helpful for another child. Visit programs if you have the time and energy to do so. There is no substitute for firsthand views.

- Stay in close touch with your child's teacher. Make sure you know what is being done in the classroom so that you can follow through at home. Share what you have read with the teacher. Ask for advice and suggestions. The two of you are a team, working for the same goals. Make your child a part of that team whenever possible. He might have some great ideas.

- Listen to your child. Only he can give you his point of view. Let him know that being different is fine. Your child will learn most from your example. Help him to think of problems as things that can be solved if people work on them together.

CHANGES AND THE FUTURE

The new parent today faces a world which is fortunately improved in many ways. The fact that his child has a legal right to education and training does not surprise his parent, and he expects programs to be provided. Consequently his attitude toward his school system and the people in it is different. He expects the vital services to be provided. He is not asking for services as if they were charity nor is he left with no option other than the institution if the few existing public or private special classes refuse his children. Some things have not changed, however, and will not, unless we make them. The diagnostic experience is often still traumatic to many parents who receive little counsel, encouragement, or on-the-spot information about where to go for more support and help. Obviously such experiences and the damage they do will simply repeat themselves with another generation of parents unless the individuals involved take deliberate steps such as the ones outlined here to avoid that possibility.