IMPACTS OF INCLUSION*

Inclusion as a central issue

in the lives of parents, teachers and children

by
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Michael F. Shaughnessy works as a psychologist at the Eastern New Mexico University, School of Education, Portales, New Mexico. Both had many contacts with parents of visually impaired children over the years. Both are convinced that parents and professionals should work as a team to get the best results for the children they take care of. It is the role of professionals to form that team. Michael and Dorine wrote this paper to enhance the chances of forming effective teams.

Parents who get a handicapped child often are not prepared for it. They may not have all the skills to cope with that. Nor do all of them have the knowledge and skills to be an ambassador or negotiator to set all the right preconditions for their child in the outside world. The outside world in its turn is not always prepared to accommodate a handicapped child. In an inclusive situation a greater appeal is made upon parents to be such an ambassador.

Dorine in ‘t Veld: “Some time ago I gave a presentation on parents’ participation. I told how we – me and a couple of other parents – succeeded in setting up an internet network, ‘the

KidsCorner', where our young Braille using children could meet. Professionals would help us and facilitate this. The parents would run the thing. We – the parents and the professionals – were a great team.
The children were stimulated very much to learn to typewrite. It's no fun to practice 'stupid typewriting', but it is fun to write a line to a friend. We had an 'internet-mother' supervising the one-liners. Occasionally she would make a phone call to clear up things.

The kids wrote more and more as time passed and started to send each other sounds (dot wavs). Sometimes they had to be stopped because they managed to overload the system.
But no one could stop them. The one-liners were now complicated messages on computer issues, incomprehensible for parents. If the KidsCorner was too small they would simply go on the internet.
The kids got independent and we parents became superfluous (in this matter). And that is how it should be. Now the children are 16-18 years old. They help us parents if we have computer problems.

This project was great fun: the children formed peer groups and learnt a lot, whilst this didn't feel like 'learning'. And we sometimes organized a meeting day. For the parents this was a great opportunity exchange experiences. Some of the 'kids' and some of the parents still are (best) friends.

I really wish all parents would have an opportunity like that: to form a group, to meet, to have fun. Not only because it is good for the parents; even more because it is great for the kids.

But it is not always easy to find people who can 'do the job'; many parents are busy, or they lack the skills or means, or they have so many problems with or because of their handicapped child. And they often have other children in the family that need their attention and time. Finally it is not always easy to form 'homogeneous' groups of parents who match and whose children share enough possibilities and interests to do things together.

Later on, when the activity of KidsCorner had been passed on to a new generation, it often proved important that I had so many contacts. I often got tips and support from my peer parents and the professionals I had been working with.

I continued the presentation stating that **in an inclusive situation it is very important for parents to network and be well informed**. You must know what is possible for your child. You must take the initiative to find chances.

For example when the child has to choose what disciplines it wants in secondary education. What if the child, like in my case, says: “Math’s, biology, physics and chemistry”. And what if at that point teachers in the mainstream school and professionals that assist them all tell you that ‘That is impossible in the present situation’? What if you do not know that in other countries it ìs possible? Exactly: your child will have to choose something else. Odds are that the child would not be happy doing a language oriented education. Worst case it might end up not being happy with his education at all and that it would perform poorly in school, not feeling good about himself, etcetera …etcetera.

When you come up with something new, you’re often told that what you want is impossible. It helps very much if you can come up with examples that give the people you have to convince the idea that it might work.
By the way: my son now does take the disciplines of his choice. There are problems of course with adapting materials and there is a huge discussion on what adaptations are necessary or allowed (!) for him to do his final exams. But so far, so good and I’m sure we’ll find solutions to get across that barrier too.

Then an old colleague of mine stepped forward and said to the public: “I would like to add something to this story. I happen to know that she has had very hard work and often very hard times to bring about these things. And I want to stress the fact that those who gave her the hardest times were we, the professionals. We way to easily say that something is impossible; we often throw up high walls for parents”.
I was grateful for his remarks. He was right. There were times when I got tired and frustrated and desperately wanted to give up. But I had no choice. If I wouldn’t do it, who would?
But there is another truth about professionals: I always managed to find some who would support and actively help me; who would work together with me as a team.
And being a professional myself I know that it is not always easy to do what you would like to do for a client. It may even be impossible to do what you think is necessary for a client or a group of clients, just because you don’t have the means: time, money, knowledge. Clients need change over time. The system is slow and inflexible; the rules or possibilities for funding or paying for expenses don’t supply the new needs.

New possibilities have to be created; it takes pioneers to do that. In an inclusive situation your child usually is an exception. As a parent you’re often alone. Information and networking are essential.”.

Michael Shaughnessy: “Inclusion puts handicapped children in an environment, which is not designed for them and amidst people, of whom the majority is not familiar with the specific (im)possibilities the child has.

Some healthy and non-impaired people cannot empathize very easily with an impaired person. To some the student with an orthopedic impairment or epilepsy is a type of alien or strange being that is beyond their comprehension.

What is life like when one cannot see, hear, talk and/or walk? To many that fate would be the end of their world, as they know it. They do not know what to feel. They may feel like pitying the person but they may be educated or socialized not to. They are educated or prompted not to show their distress, but often they feel very uneasy.

Focusing on Inclusion: being included is the opposite of being excluded. If we say "inclusion" do we mean attending a school that practices **inclusion** or **mainstreaming**? What exactly is inclusion? Is not an impaired person **excluded** from certain possibilities and thus activities and social processes?

Let us take something very simple and something that occurs on a daily basis, such as a conversation in either a classroom or a schoolyard. It has been indicated that 80 % of our communication is non-verbal. And sometimes communication goes without any words at all! Gestures and just looks can be very effective to communicate very important, emotive and evocative messages. The situation doesn't always allow that these messages are translated into words for the blind or partially sighted person who is in the group. Besides, most people use non-verbal communication and respond to it, never really thinking of it or translating what they think they observe into words. Anyway, the child without eyesight will miss out on much that goes on in the group or class. It is not totally included.

Even when accommodations and modifications are possible, **full total inclusion** may be unrealistic in many situations. It may be better to focus on "to the **maximum extent possible**" and to **allow professionals to make determinations** as to what is reasonable, safe and appropriate".

Dorine: "What is **full total inclusion**? Doesn't a handicapped person have a right to be different? Aren't we all different? If two persons participate in the same group in an activity or read the same book, won't they have different experiences? Each of them may think other things important, remember other details and draw different conclusions. As long as they stay on speaking terms, they can communicate about that and not exclude each other.

Of course if one person cannot see and the other can, it may take a little more explanation; but this can make the cooperation even more interesting.

I used to say that having a blind son broadened my mind; I use my ears and nose and tactile sense a lot more consciously!

If you say ‘to the **maximum extent possible**’, the critical point is: what is the maximum extent possible?

Firstly, it’s not always obvious to a sighted person, why something could be fun or important for a person without eyesight.

For example: I know of blind children who play advanced levels of Nintendo games and love it. (Meanwhile they train logical thinking, ear-hand coordination and concentration, but that is not what they do it for of course). And they may gain the esteem of sighted peers or siblings.
Another example: I know of a blind boy who attends every match of his favorite football team in the football stadium. Many sighted people cannot imagine what’s in it for him to go ‘looking at a football game’ whilst he cannot see. Besides: as a matter of fact, I cannot imagine why sighted men like football ☺. He loves it. He brings a radio so that he can hear what is happening. And he enjoys the atmosphere. Afterwards he enthusiastically and fully participates in recaps and discussions. He has found out all there is to know about playing football. He has a great time. That’s what’s in it for him. He enjoys football games his own way.

Secondly, if you are willing to look at things from a totally different perspective, you might find reasons to (want to) broaden up the maximum extent possible. Like in the example you gave: you might train the group to verbalize the non-verbal communication. You’d be surprised on the decline of the number of misunderstandings and wrong assumptions that are caused by misinterpretations of facial expressions or gestures! In fact you train the group to give and take feedback! Everybody would profit from this. But then of course it takes a situation and a teacher who can do this.

Thirdly, there’s a danger in ‘allowing professionals to determinate…’. I’m not talking about allowing a child to make a lot of noise in a classroom when it should be silent or other obviously inappropriate behavior. I’m talking about excluding the student from participating in a class activity, for example collecting plants that will be examined in class. Wouldn’t there really be a way to let the visually impaired student participate, preventing him from walking into ditches or stinging nettles? Of course there is. Many professionals will make these determinations very scrupulously. But I’m afraid that too often I heard: ‘This child cannot participate because it would be too difficult (or dangerous or not amusing or whatever!) for it, because it cannot see” as an **excuse to be able to exclude** it. Because that was **easier.**
Understandable, since many teachers have a very full program even without the special needs student. But often a small investment pays back enormously! Yet this defensive wall is frustrating and particularly hard to fight.

Finally: the child may be deprived of great opportunities when others decide for it. If it participates in the class activity it may find that it is extremely fatiguing because of the concentration it requires. But it also can prove very rewarding for another child, who loves being in nature and strolling about, finally finding out what kinds of plants grow where”.

An effect of exclusion is that handicapped children are often denied the chance to learn and to find out for themselves what they find difficult, nice, exciting, etcetera, from their own perception.

These points were given so much attention by Michael and Dorine, because they are the core, according to them, of what inclusion is about. To realize them it takes pioneers, both parents and professionals. It takes (enough) conservatism to help keep the pace and keep upright the good attainments.

We already mapped some impacts of inclusion on parents, teachers and children. Now let’s continue.

Impact on teachers

Inclusion may put an inordinate amount of pressure and stress on teachers. This is regularly enhanced by the fact that teachers are confronted with the reactions of parents of “normal“ children who are afraid that their child will get less attention or that adopting a handicapped child will have negative consequences for the academic records.

Some teachers will see it as a challenge or enrichment to have an impaired student in their class. Others, with another personality or just less fortunate circumstances, may panic when they are faced with too much ‘diversity’. Firstly, teachers are often confronted with several special needs students in one class. Secondly, many teachers are able to make the accommodations and modifications needed for mildly handicapped students, but not for those students who have very specific visual, auditory or other needs.

Some may experience the visually impaired child as a burden. They may try to hide it, more or less successfully, because they think this is politically incorrect. They may act as if ‘nothing is wrong’, tell everybody that the child behaves very good and is very nice to have, but in the meantime not meet the special needs or possibilities of the child. At first everything seems to be going well, but when time passes this may lead to problems, because the child never was taught to do something since the adult avoided the problem.

Others who experience the child as a burden may say the child is difficult or not so intelligent, so as not to be blamed themselves.

Teachers need to prompt, encourage, push or, if need be, cajole impaired children just like any other child. Some teachers have no problems here. But many teachers are insecure because they are ignorant of the (im)possibilities of the child, prejudiced or just over-protective, afraid that ‘something might happen’, or because they have great emotional trouble being confronted with a handicapped person.

It is not good when, for example, a teacher is not able to express his distress, and just on the outside shows correct social behavior! But expressing his or her distress towards the child or its parents may hurt their feelings. A delicate matter!

Impact on the handicapped child

Some impaired children quite naturally help their helpers and indicate what they can or cannot do or why they do or don’t want to try. Other kids have trouble accepting help because they don’t want to be a burden. Yet others have found out that they can take advantage of their handicap and even manipulate, thus having others do things they don’t like so much. This of course is a wonderful recipe for trouble in the class!

It is logical that handicapped children may face (many) more problems than not handicapped children. But that is not the problem. As long as they have a chance to learn, as long as they are not overprotected and as long as they are respected, it is even very useful to learn to cope with all these difficulties. Nowadays in modern countries many parents want to eliminate all problems for their children; their youth should be one big party. That is not healthy for any child, handicapped or not; these kids are spoilt.

Some impaired included children develop quite well and stable. For others it is much more difficult. They feel unhappy or they are bullied, they come home with psychosomatic complaints. If interventions do not help it may be good when they can have a time out in a more protective environment, together with peers. The same goes for children who live in a problematic home situation or whose parents are temporarily overburdened.

When children need therapies or medical treatment, this can lead to overburdening. As can all the extra things blind students have to learn and practice, like mobility, Braille reading and writing, working with assistive technology, social and practical skills, especially when these things are not integrated in the school program.
A risk for impaired children is that they – and their families and their teachers – are being over-monitored. Every little problem or dip is enlarged and analysed. Some children even speak a very adult or even carers’ vocabulary. That of course is not very including.

Impact on family life and on parents

Parents often feel very much thrown to themselves, or left to their own devices, or ingenuity or creativity in dealing with the day to day problems of raising a child with a disability or handicap. Of course, this is more so when their culture does not support or even understand inclusion. It will differ per person and vary with the seriousness of the handicap.

One thing seems to be common: when parents have to fight to get inclusion realized, they easily may be frustrated and exasperated by what they see as an uncaring bureaucratic institution.

Not having a familiar perspective can be very destabilizing. Most parents experience a painful phase of coming to terms and acceptance. It may be difficult to consult the normal network of neighbors, friends and family when none of the persons involved is experienced with the impairment. Sometimes close relatives, e.g. the grandparents, are very upset themselves. Instead of being able to support their children, the parents, they need to be reassured by their children that they are doing fine. Nothing can be done 'normally'. Next they have to learn many things, concerning the handicap, aids etcetera. Often raising their handicapped child costs a lot of time because of the special care their child may need. Parents may need lots of time consulting doctors and therapists with their child. Parents have to be sparring partners for doctors, therapists, teachers. They have to practice with the child as the expert prescribed.

Parents need to be examining and exploring all options and taking a very long, clear look at the assistance that can be offered. Parents want the best for their child. That could be:

a) Their child is the same in a very exceptional, supportive environment
b) Their child may be very different, but in a normal environment.
c) The same in a normal environment where it is accepted that there are special rules and special procedures if the handicap or medical condition requires it.
d) The child is fully included with other average students and teachers, parents and children are all happy with the situation.
e) Full inclusion in a private school which caters to the needs of that child.

Parents may have been to a great many different schools and seen differing approaches in both large and small schools. Once they found a school for their child, parents may need to make a good many visits to their son's or daughter's classroom to ensure that the teacher is doing what he/she said he/she was going to do and to observe the behavior of that child in the classroom.

For parents, the lives of their children are of critical importance. The quality and quantity as well as the degree of inclusion in school and extra curricular activities for their children are of paramount importance. Parents realize that their child's education serves as a foundation for the procurement of skills for the rest of their lives and that every effort should be made to maximize the time spent in an environment that is supportive, nurturing, caring and challenging.

Notwithstanding all the problems they face there are many parents who choose inclusion because they believe that their child should not be segregated from other “normal“ children and that they should be educated as normally as possible, in a healthy social environment, living with their own families. They are committed to realizing a “normal” family life and childhood for their children and working towards this goal and advocating for their children.
But how “normal” is family life? How does one arrange all of the extra support, knowledge, and time that one needs as a parent to realize inclusion or even full inclusion. Having an impaired child often brings tension into marriages. Fighting for inclusion may cause even greater tensions, especially if both parents think differently about the inclusion of their special child.

In some instances, siblings are literally burdened with the care of their sibling. Many children resent this added responsibility and the loss of their childhood. Instead of being outdoors and playing, they have to provide supervision while mother goes to the store or performs ongoing routine household tasks. This may lead to problematic relationships and tensions within families.

Many parents struggle with unresolved feelings, for example

- About the disability or medical problem or inadequacy of the child;
- Or because they blame themselves for their child’s disability.
- Because they continually had to face surgery after surgery as the doctors attempted to rectify or fix the problem.
- Fear for the future; one day they will not be around to ensure that the needs of the child are being met.

This may lead to logical but often counterproductive reactions like

- attempting to make up for the error or deficiency that they see in themselves.
- over-investing in one child to the exclusion of the needs of the other siblings, their mate, spouse or themselves.

These reactions often complicate matters even more.

For these parents, there is no simple answer or solution, nor will there ever be a simple answer or solution. Many parents search for counsel. Some counselors listen, listen well, listen empathically and others offer suggestions, advice, support groups, books to read and offer what may have been helpful to other parents.

Some counselors take a very blunt straight forward approach and simply indicate that the parent is going to have to learn to deal with and cope with the schools, their child’s difficulty and adversity.

Suggestions for improving the inclusion process

International exchange
It is very interesting to see how in some countries role models are used. For example: blind students visit parents, explaining to them about mobility, Braille reading, social skills etcetera. It gives parents hope and makes a lot of things more acceptable and ‘normal’. Teachers and parents should have the opportunity to review other inclusionary processes and procedures, and to see what other nations are doing.

Peer contacts for handicapped children
Peer contacts are important for handicapped children in mainstream schools; they often have no children their age in a similar situation in their school or neighborhood. We could organize specialist courses or e-learning classes for homogeneous groups (problematic disciplines). The supportive use of the internet for specialized education offers great possibilities.

Integrate extra’s in school program
Extra courses, therapies and activities should be integrated into the (mainstream) school program of the child to prevent an overburdened program or a program that doesn’t meet the special needs, like learning special skills (social, ICT, mobility, adapted sports, etcetera).

The system is more innovative and less bureaucratic.
Not all parents have the skills to advocate effectively for their children. It shouldn’t depend on the parents, whether or not the handicapped child gets the education that it has the talents for. The system of provisions should guarantee that children get what they need.

Training and coaching, help in communication
We’ve seen that communication is a major issue and we’ve seen what can complicate communication and cooperation from both sides. In many cases a coach or supervisor to monitor the inclusion process would be very useful. For many schools and teachers, inclusion is a balancing act, which may also require in-service training and consultation.

Counseling
Often, parents, grandparents, siblings, teachers and the impaired children themselves may need counseling to get to terms with unresolved feelings, doubts and negative emotions they have to face and deal with.

Cooperation between parents
Both the importance of parents working together and the difficulties realizing it were mentioned before. Professionals and institutes might facilitate parent groups or parent organizations.

Cooperation between professionals
Too often professionals do not coordinate their programs, treatments or lessons.

Cooperation between parents and professionals

When two experts - the parent as the expert on his child, and the professional as the expert in a certain discipline - work together, each from his own role, results can be better: Working as a TEAM means: ‘Together Everyone Achieves More’.

Confidence

It is important that all partners involved in inclusion have confidence in each other. Only that way cooperation can be fruitful. And there is a good reason: there may be huge differences in personalities, cultures, circumstances and available means, but basically parents - as well as teachers and professionals involved - share the wish to have the best possible education and future for ‘their’ child.

Attitude

Every child needs (a) person(s) who believe(s) in it and has positive and realistic expectations of it. You either live up to your expectations or you live down to them! And children either live up to the expectations of people around them or down to them.

Once a child feels emotionally and psychologically well it can learn and develop in a positive way. Preferably the parent(s) is (are) a firm and constant candle. But let’s not forget: each small candle lights a corner of the dark; each teacher or professional may contribute here; maybe briefly, but significantly. Where systems may make it difficult or even impossible to realize everything you think would be best for the child, this is something to keep in mind.

Finally the attitude of the child is important to work on. It will often have to fight to get things done, to accept and deal with disappointments. And then find a new way. Empower the child by believing in its possibilities. Attitude is of utmost importance. Remember: it is not your aptitude, but your attitude, that determines your altitude!

When we use the word ‘professionals’ in this paper we mean:

- the people who are in direct contact with the child or its parents (mainstream teachers, itinerant teachers, therapists, psychologists, social workers, doctors, etcetera)
- their managers
- policymakers
- people working in institutes that more remotely support handicapped children and their parents (suppliers of teaching materials, assistive technology, etc.)

Afterword

Maybe the question pops up: shouldn't we go back to the old situation with special (boarding) schools? Considering the reasons why inclusion started, that does not seem a good idea. There were enough problems then too. And there were pioneering parents and professionals who wanted to improve the situation. However, it is worthwhile to see what good things of the old situation we might want to preserve or restore:

- The environment – buildings, aids, staff and learning materials – meets the needs and possibilities of the children. This can be important to develop self confidence and skills. Once these are gained the child is up for more difficult situations.
- All extra care needed: therapies and special trainings, are coordinated and can generally be performed in school time.
- The child has time to relax and participate in nice and social activities after school time.
- Peers who face similar problems are at hand.
- Specific knowledge is available in a central place. Specialists frequently meet and exchange.

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