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Mixed Feelings: A Parental Perspective on Early Intervention

Lisa Bridle, Glenys Mann

A paper presented at the National Conference of Early Childhood Intervention Australia, Brisbane, June 2000.

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Parents of children with disability are often enthusiastic supporters of early intervention programs and are happy to participate in home therapy. This involvement can have many benefits but also raises a number of issues for parents and families. These include

- 1) the impact on parent-child relationships when a parent takes on the role of "therapist" or "teacher",*
- 2) the pressure and guilt associated with feeling responsible for your child's development, and*
- 3) the impact on family routine and other family members.*

Parents, particularly mothers, may also feel compelled to present themselves to professionals as "good", "responsible" and "coping", thereby possibly limiting their decision making and missing opportunities for support for themselves. Concerns exist regarding whether extensive therapy can send a message that the child is unacceptable as they are and needs "fixing up". Parents must grapple with the extent to which the optimism that accompanies early intervention merely delays an acknowledgment and acceptance of the child's impairment.

Lisa, a social worker, and Glenys, a teacher, are both mothers of young boys with Down syndrome. This paper will present a parental perspective on these issues. The paper will build on ongoing conversations between the presenters and other parents of children with disability.

The ideas in this paper have been jointly developed through numerous conversations. Together we take responsibility for the questions we raise and the conclusions we have reached. We have, however, chosen to speak to you personally, from our individual experiences. We apologize for any confusion this creates for the reader.

*So you are able to track the speaker/writer for individual sections we should explain that Glenys is the primary author of the sections titled *The New Parent, Positive and Supportive Roles of Early Intervention, The Messages of Early Intervention, the Introduction and Conclusion*. Lisa is the primary author of the remaining sections.*

Lisa would like to acknowledge the use of quotes from her interviews with mothers of children with Down syndrome, conducted as part of her study on decision-making around prenatal testing. She would like to thank these research participants for their contribution and insights.

Introduction

In the years that Lisa and I have been learning about Down syndrome, we have discussed many times what this diagnosis means for our sons, and what it means for us and for our families. Early Intervention has played a large part in our lives over these years, and so has obviously come up for discussion on numerous occasions, not only between ourselves but with other parents from the Down Syndrome Association of Queensland. We have titled our paper "Mixed Feelings" because our experiences with the "Early Intervention System" have given rise to a variety of different, and sometimes conflicting, emotions and thoughts. We have grabbed this opportunity to share our experiences with you because we believe that for all the good that early intervention continues to do, there are questions that still need to be asked. We believe that to grow in our understanding of disability we cannot just continue along the same paths without talking things through and questioning why we are doing what we do.

Our aim is, through the sharing of our feelings and experiences, to describe to you what early intervention has meant to us and other families. That even with the best intentions, the "system" may not necessarily close the gap between those with Down syndrome and the community, but continues in its own way to keep the child separate, different, defective, as a patient, a consumer or client. As mothers we have been challenged by the struggle between how we see our children and how the world sees them. We hope to challenge you, also, to rethink the "messages" of early intervention and the attitudes that drive the disability system in general. We don't claim to be stating any "truths", to be speaking for all parents, or to have any clear cut answers but simply offer our views and our experiences with the hope that the questions we raise may move us all a little closer towards doing things better.

The New Parent

To begin at the beginning, what happens to new parents when a baby with Down syndrome is born? Of course all parents are different and will react to the news that their baby has Down syndrome in their own ways, but there are experiences and feelings that seem to be common to many parents and families. These are quite well documented and acknowledged by those who work with new families but it seems important here to begin this paper by trying to get a feeling for this reality - to try to understand as fellow

human beings, rather than as professionals, what it is like to be told that your new baby has a disability. Just what do parents bring with them to the experience of early intervention and to the relationship with therapists and service providers?

It is very difficult to explain the reality of the emotions to someone who hasn't been there. While it may be easy for me to list the feelings of grief, shock, fear, disbelief, anger and worry that are so well documented in the disability literature, it is much harder to capture the vulnerability and disconnectedness that I felt in the first year after Jack was born. Like a lot of parents, my inexperience and lack of knowledge left me feeling very inadequate and desperately in need of some direction. I read anything I could get my hands on (not exactly a wise move, considering some of the stuff that is still in circulation about Down syndrome) and sought out other parents for guidance and hope. In the confusion of trying to deal with this unexpected turn of events, there was almost a panic of needing to be "doing something" - looking for information, searching for answers, trying to find some reassurance, some link with "normality". Like many parents I entered a completely unknown world. Like many parents I knew nothing about Down syndrome, what it meant for my child, my family, or for me. Like many parents I knew nothing of "the system" or of disability in general. Like many parents, all I had were fearful, vague memories of people with Down syndrome and a host of negative beliefs that were unrealistic and out-of-date.

This frame of mind, I believe, can leave many parents very vulnerable to the advice and opinions of the early intervention team and other professionals. It is often suggested, and rightly so, that families need to be involved in decision-making processes and that programs need to be built around what individual families want. What worries me is that at this stage many parents don't know what they want, and are in some way, just "surviving" day to day. They have barely come to terms with the initial shock, let alone what Down syndrome means on other levels. Even the most well-intentioned therapist has, potentially, a lot of power over the attitudes that will be developing in this painful and sometimes fragile situation.

Then, of course, the individual does not operate in isolation. Our decisions as to what is "best" for people with disability and their families, cannot but be influenced by our long history of community attitudes towards disability. No matter how liberal, tolerant and

“inclusive” we now feel ourselves to be, we all still come to the experience of early intervention, families and therapists alike, with our own history and discomforts. We grew up in a generation that separated people with disability, isolated them and denied them even basic human rights. We had few, if any, experiences of valuing these people or even of relating to them in any usual way at all. So although we may have moved away from a belief that people with Down syndrome need to be segregated, I’m not convinced that we have replaced this with a “solution” that is really very different in its acceptance of people with Down syndrome. I would question how far, in such a short time, we can as a community have come in our underlying feelings towards disability. Perhaps we have a “kinder”, seemingly more “accepting” attitude, but what have we done to really challenge the notion that to be “acceptable”, people with Down syndrome have to be like “us”. It is my belief that we have a long way to go, and that includes me as well, before we truly value people with Down syndrome for who they are, instead of always linking their value with how competent they are.

Encompassing even our notions of disability, are the values that are operating within the wider community. What chance does a person with Down syndrome have, when the demands on all of us exceed what most of us can live up to! Our community has become increasingly focussed on money, appearance and intelligence. Even for the best of us, it is difficult to make the grade. Parents stress themselves out spending time, effort and money to ensure that their children have the best chance of “fulfilling their potential”. The pressure on families in this competitive “climate” makes it easy to understand why it seems so necessary for families of children with disabilities to do all that they can so that their children will “fit in”. It is certainly confusing to live in a society which, on the one hand values “the individual”, yet finds it difficult to tolerate difference.

So what do parents come to early intervention with? They come with their own confusion and lack of knowledge about Down syndrome and most likely negative images of the future for themselves and their child; a collective community history of banishment and ignorant attitudes towards people with disability; a general community trend towards intolerance of anything that is less than perfect and an urgency to somehow be making sense of all this, to do what is “best” for their family. There is little or no space nor perhaps even the inclination to actually “see” their new child. There may be few opportunities in the early years to consider the possibility that even with the disability, he or she may be a very special and unique individual that actually has something to offer. The early intervention experience undoubtedly has the potential to play an important role in this situation and can be a vital connection and support for new

families. I have personally had valuable experiences through the early intervention team and I know that other parents have felt the same.

Positive and Supportive Roles of Early Intervention

My initial contact with the early intervention team felt rather like a “rescue”. In my vulnerable state, the therapists certainly helped to give the early months some meaning and I looked to them for a direction through the maze. My continuing experience over the next six years was in many ways very positive. I developed a strong relationship with the team, listened to their advice, sought their guidance on many occasions and never doubted their commitment to doing their best for me and my son.

There is a great deal of comfort to be found for parents in being with members of the early intervention team. Instead of dealing with the ignorance and insecurity of our families and friends who are also struggling with the news, here we have a group of people who are very comfortable with the situation, with us and with our children. Here are people who have experienced this before, who do have a plan and do have suggestions of “where to go”. The attitudes of the team had a very positive effect on how I viewed my son. Their optimism towards him and his future, their affirmation of the value of people with disability generally, was a wonderful model for me and had a tremendous impact on how I moved forward in my relationship with Jack. I do not doubt that the early intervention team has a powerful potential to generate a positive and hopeful outlook for families.

I found the early intervention team to be an important source of information, both about the disability itself and about how the family deals with things in general. They were a link to information about other services and community groups, knowledge that is very important and yet surprisingly difficult to tap into. I attended a number of workshops and listened to guest speakers that were organised through early intervention. It definitely became easier to feel confident the more knowledgeable that I felt.

The early intervention team was to be a “constant” in the early days of uncertainty after Jack was born. Therapists on the team shared what felt like a burden at the time, the weight of seeking out learning opportunities, planning what I could do that was best for my son. The team often acted as a sounding board as I tried to come to terms with what having a child with a disability actually meant. They offered another perspective on Jack’s progress and when this seemed slow would notice small steps that perhaps I was too close to see. They kept me on the move, making sure that I didn’t underestimate him for too long but had clear and appropriate expectations of what he could achieve.

Working with the early intervention team may serve a functional purpose while parents are still in a stage of grief. To feel that they are doing something constructive, to have goals and activities for their child may in itself be therapeutic for parents. Feeling that they are contributing to their child’s development may be a lifeline to parents in the early days of coming to terms with their child’s disability.

The messages of early intervention - the start of our misgivings

So, at the time, I was certainly grateful for the information and support that I was able to receive from early intervention. It would seem that other parents also appreciate this support, so this clearly meets a need. Just as important, though, and maybe more so, is the opportunity to talk to other parents. This is possible through parent groups like the Down Syndrome Association and Queensland Parents of People with a Disability but for some families it is only through the early intervention team that this contact is made. I think it is significant that my first real glimpse of what my attitude to Jack could be, was at a morning with parents from QPPD that had been organised by the early intervention team. The memory of the tiny seed of hope and “rightness” that I felt at that meeting is still very vivid. I remember a clear shift in my own attitude as I listened to parents speak passionately about a vision for their children. Their boldness and courage in daring to think differently about disability, in defying the system, was the starting point on my own journey to work out what I wanted for Jack. This was a new focus, a subtle difference in attitude that emerged when I could look through another parent’s eyes rather than those of the professional.

We are throwing into the “disability debate” the possibility that, while early intervention has much about it that is worthwhile and positive, the whole “culture” of therapy may actually “feed” the fear and negative attitudes that new parents initially feel. We are suggesting that from the moment parents find out that their baby has Down syndrome, the “system” inevitably damages the relationship with their child. The way news is given, the behaviour and language of staff, the reaction of family and friends - the value judgement that lies in each response to families has the potential to cause a blow to that fragile link between parent and baby. Does early intervention help to allay these attitudes or does it actually embed them further? Sure the relationship and support makes parents “feel” better but does it do anything to challenge and break down attitudes towards disability? The whole approach of programs which respond to the deficits of a child and then seek to “fix these up” so that the child will be better equipped to “fit in” to the system, operates on a basic assumption that the child is not okay. How does this affect the tenuous and crucial relationship between child and parent and

even more importantly how the child learns to see himself?

The implications of being a therapist to your child

We believe we need to think seriously about the implications of parents becoming therapists and teachers to their children, particularly to their children with disability (see also Rodger, 1986). As parents we teach our children a great deal, but this is usually a seamless part of our very multi-faceted roles as a parent. With our children with disability this role threatens to overwhelm these other roles. It may even undermine the integrity of the whole relationship. Michelene Mason (1995) claims that there are many aspects to the way parents of children with disability are introduced to their children which damage the parents' ability to love their child unconditionally. One of these aspects is parental over-involvement in therapy:

When parents are turned into therapists or educators for their disabled children, the children may well feel that the love which they so desperately need is conditional on their performance in the getting better game.

Kerry described her initial response to her son's developmental delay as "panic and overdrive":

The hardest part is like not knowing...being told that he won't walk till he's two and he won't do this and all the different things that they're so much slower at. So like I just sort of went into panic and overdrive and I've got to do all this sort of stuff, which I guess in some ways....not that it was a benefit but because I didn't have any other children to worry about, I could concentrate on Stephen which kind of became my life.

Parenting is, of course, hard work and for most mothers this job overshadows other responsibilities and becomes our "life". For many vulnerable parents of children with disability, particularly in those early months of adjustment, the impulse to "work" with your child rather than enjoying a relationship with that child can be difficult to resist. Even when the relationship with the child is established the "work" and the focus on the future can interfere with enjoyment of the present, as Ingrid explored:

If we just had regular babies, I wouldn't be pushing her all the time to try and do all these things. I don't think I should be worrying unnecessarily about trying to teach her to read at the moment but I am. (Laughing) If I had another 17 month old baby I wouldn't be thinking about (that), you know I'd read them stories but I wouldn't be thinking about how I'm going to teach them to read at this stage. A lot of the things that I think we should be able to sit down and enjoy, I don't

This is not an argument against early intervention, but a caution that people who work with vulnerable families must be vigilant in encouraging families to remain parents first and not to allow therapy to get in the way of living and enjoyment.

enjoy as much as I perhaps should, because of that.

This quote captures the pressurized existence of the mother of a child with disability. This mother who is worrying about teaching her daughter to read has many other stresses which are not revealed by this quote. Her daughter has had multiple medical problems and severe feeding difficulties. These are however the "givens" of her situation and she does not choose to focus on these as the aspects which threaten her enjoyment of her daughter, but rather the feeling that she is always pushing her daughter and herself to "do more".

Micheline Mason claims a distinction between play and therapy: "Play is about the child's goals; therapy is about the adult's goal" (Mason, 1995:11). Certainly we will return to this theme of the impact of adult directed "play" but I would also like to stress here another distinction between play and therapy. Play is "fun" and therapy is serious. In therapy it is important that the child attends to the task and "achieves". Enjoyment and relationship take a back seat to the "task" and the "goal". I look back at how much my attention to Sean in the early months of his life was performed almost mechanically, without a sense of fun certainly and almost without a sense of unique connection to Sean at all. I could have been performing the same manipulations on anyone or anything.

It is a great tragedy that many of the joys of parenthood and family life are initially perceived by many parents as "wasted time". Many parents, like Jennifer, look back on their early frantic attempts at infant stimulation with regret:

The thing that I resent about the whole business of Nick's infancy/babyhood is that I never actually took the time to just play with him like a baby. I always thought OK, the most important thing to do was stimulating him, ok, have him sitting up... instead of just bloody enjoying it.

I don't remember just lying on the carpet with him, looking at the sun and blowing on his tummy, just the silly simple things that you remember doing. But I was so sad with Nick that I didn't

just understand that. I was so busy just dragging him to this appointment, that appointment, staying in hospital, all those things, rather than the things that really matter like, tickling them and looking at them...and no-one told me that, it was just something I felt driven to do.

In these comments there is a strong sense of loss around the "things that really matter" and a recognition that play and therapy are not the same thing. There is also a statement by Jennifer that she chose to embark on this course without explicit instruction from professionals. This approach is however so common among new parents that I would contend that there are implicit messages encouraging parents to do just that. Jennifer is not alone in grieving and regretting that "lost" baby time. While most families move out of a "panic and overdrive" response to achieve a more balanced family life, I wonder about the long-term implications of this loss. I also fear the implications of the unwitting message which we send to our children; that we value them for their "progress" rather than for themselves.

This is not an argument against early intervention but a caution that people who work with vulnerable families must be vigilant in encouraging families to remain parents first and not to allow therapy to get in the way of living and enjoyment. It is necessary to reassure families that it is possible for their family member and themselves to have a good life despite their child's disability and that a positive future does not depend on an overkill approach to therapy. Parents need to be supported to trust that decent lives for their children will depend foremost on decent relationships and that the parent-child relationship is crucial in establishing a foundation for these future relationships.

Pressure and Guilt

Becoming "therapists" to our children is a major source of the pressure and guilt associated with parenting a child with disability. While there are other stresses in parenting a child with disability it is the constant questioning of whether one is "doing enough" which most threatens many mothers' enjoyment of their child. Mason claims that this is also likely to impact on the child's self-esteem:

Enjoyment is the last thing on the agenda when talking about parenting and disability, but without this the child feels that he or she is the cause of a lot of stress and anxiety for the people who love him or her, which of course is another erosion of the child's self-esteem. (Mason, 1995:11)

Many parents would identify with the undermining of a sense of joy and fun with

their child with disability. The experience of having a child with a disability often feels “heavy”, serious and stressful. I have often thought about what makes that experience stressful and come to the conclusion that it has very little to do with the characteristics of Sean and very much to do with my own fears and my struggle to accept him as he is without trying to “improve” him.

There is very little about Sean’s behaviour that is particularly challenging and demanding, though admittedly Sean’s past absconding or throwing, did seem, at the time, highly challenging. And there are days I sincerely regret breeding with a man who could run ensuring my son’s genetic inclination towards speed! Mostly, however, what I have found stressful is a mental consciousness of all the “to do’s” in my life and my concerns about how Sean is perceived by the outside world. There have seemed always to be too many items on my “to do” list with Sean—gross motor, fine motor, speech, behaviour management, concept development, toileting. Particularly in the beginning there seemed to be no opportunity to take a break from “working” with Sean and little time just to delight in him.

The effect of much early intervention has been for me to focus on what Sean cannot yet do at the expense of celebrating and wondering at all that he has achieved. The effect of knowing too much about the minute stages of child development has been to become at times completely demoralized. There is a spotlight on our children’s development that is a constant reminder of their failures. This knowledge allows us to focus considerable anxiety on what it might mean for our child’s future that they cannot place a block on top of another in the prescribed age range. How much of that development with our other children passes unremarked (and I feel relieved that it did!) There is a loss of trust in the natural, albeit slower, progress in development. This loss of confidence in our children, the focus on their limitations and fears of the future create a mental pressure which intrudes on our relationships with them.

In my own research many parents have spoken of the mental tasks associated with mothering a child with Down syndrome. The future goals both short and long term are always in one’s consciousness as is an awareness of the barriers you may face in having your child accepted at childcare, kindergarten or school. It is said that guilt is an occupational hazard of motherhood generally but for mothers of children with disability, the guilt is more intense and unrelenting (Bowman and Virtue, 1993). It feels like no effort is ever going to be enough to nurture your child’s development. There are always more activities to take your child to, more research suggesting critical actions you should take, more home activities to follow-up from therapy sessions.

I have a lot of guilt at times because I think there’s so much more I should be doing with Sarah. I should be taking her dancing and I should be taking her to swimming and I should be taking her to singing because I know all of those things (would help). Then I look at my week and I think well, when on earth am I going to be able to fit it in? So yes, there certainly is pressure for us to be doing all those kind of things, and I look at her and I think yeah, maybe she would be talking better if we were doing singing lessons um, and then I just have to stop and think well, you know, we’re doing the best we can at the moment

The constant accounting about “Am I doing enough?” weighs heavily:

Well I think it’s difficult for me because it’s almost like well, you feel guilty because am I doing enough? Am I doing this exercise (enough)? When it was physio, am I doing enough with Clare? Am I doing enough speech stuff now with her? Am I reading to her enough, all the kind of OT things? Am I being too impatient when I’m letting her feed herself? I’d say all of us get the guilt thing.

Ironically it is often the “simple” exercises which impose the most pressure. The suggestion to “just do this at bath time” or “dinner time” guarantees its impossibility. There are always a hundred competing demands which ensure the exercises are frequently missed and it is so easy to track your failure to complete them!

The guilt also extends to self-doubt about how effective one’s approach may be:

Not having a background in teaching also (I question) am I doing this the right way? Is this being effective? Because I know with these kids you’ve got to persevere, persevere, persevere, but am I persevering and doing the wrong thing? Or do I need to leave it for awhile?

The urgency to keep persevering can often be experienced as a constant pressure:

I knew every skill Darwin should be attaining at each age level but was not. I had the mistaken belief that there was a direct correlation between the time I spent working with Darwin and his ability to keep progressing. On days he “worked” well I felt a sense of accomplishment; on days when he wouldn’t stack his blocks or refused to scribble with a crayon, two items which ALWAYS appear on developmental evaluations, I felt a sense of defeat. I felt compelled to spend most of my time at home working with him. It was only when he was asleep that I would allow myself to relax. Often I felt exhausted (Carter, 1993:67).

If early intervention is an erosion of the child’s self-esteem the constant pressure to keep going and the sense that even greater efforts are needed can undermine a parent’s self-worth. Kerry’s comments underline how much parents sense of achievement and worth becomes tied up in the child’s achievements:

I think as the milestones get bigger, they require more effort and you’ve just gone through a major milestone and all of a sudden you’re working up for another one. There’s really not much rest in between to enjoy and say “Excuse me, look at me I’ve done this,” but then you’re working on the next one.

Parents describe being much harder on their children than they would otherwise be. If parents are feeling exhausted by this constant pressure to perform it is likely that the child is also experiencing the negative impact of living with the constant pressure and parental swings between hope and disappointment:

Before she smiled I remember thinking if she just smiled so I’d know that there’s something going on there, I’ll never be anxious for anything else, if she’ll just do this I’ll just sit back and accept everything else as it comes but then the next thing .. if she’d just sit up .. if she’d just stand up, if she’d just crawl...

This bargaining for developmental strides does not disappear but can become more intense as development is seen to lag further behind. The “potential” of any child is so unknown that even if one makes the decision to fully devote oneself to your child’s development, there will always be opportunities you did not provide for your child and the nagging guilt that your child may be “better” if you had. It is a brave parent who is able to resist that pressure. Again we need to consider the “losses” which are present in “doing everything” for our children. Certainly there is a loss of the potential for an unconditional, joyous and relaxed relationship, a loss of spontaneous fun and a loss of unstructured time to explore. The experiences which are lost may provide alternative opportunities which are too valuable to surrender as readily as we do.

The “ultimatum” and the meaning of disability

As others have noted the “so much can be done for these children now” becomes more of an ultimatum than the encouragement intended” (Leeson and Opolski, 1988:272). One mother whom I have spoken to reported that when she asked her doctor soon after birth what she could reasonably expect from her son, she was told “it’s up to you”. This was surely a cruel response to a woman post-labour and reeling from the shock of the news that

her child had Down syndrome. I believe that it was also a highly inaccurate response. I would hope that professionals would be courageous enough to stress to parents the unknown future of any child. While there may be a place for optimism and information about the resources available to support a child's development, there is no place for comments which suggest that the whole future of a child depends on an extraordinary level of self-sacrifice on the part of parents (read mothers!).

It seems that we have rapidly moved from a medical attitude of "There's nothing that can be done for these children. Institutionalize them!" to "Everything can be done for these children and you'd better do everything you can!". I believe that both attitudes reflect a deep discomfort and rejection of disability. While disability may not be ordinarily considered a desirable feature, it is a feature which it is possible to live with very happily, even without extensive intervention. It is even a feature which represents normal human variation. People with disability remind us that it is not the disability itself but society's reactions to disability which are the most harmful and limiting (Davis, 1987; Morris, 1993; Newell, 1994).

Many parents understand early intervention to include an idea of urgency and a critical time period which is "make it or break it". To some extent unfortunately this is true. Parents perceive that their best way to secure a place in a regular school setting is to make their child as competent as possible. Further they realize that once a child hits school that their access to therapy will be severely limited unless they are able to afford to pay for these services privately. How different this picture might look if parents could be assured that there would be adequate educational services available to support their child's lifelong learning. The problem lies not with providing children with disabilities with learning opportunities, but with the pressure, guilt and desperation which early intervention can invite. The problem also lies with believing that "reducing" the appearance of disability and "passing" in normal society, is the only pathway to a decent life.

Self-presentation

Another pressure mothers face is presenting themselves to professionals as coping and competent parents. In the early months of my son's life, I remember the stress of preparing for the physiotherapist's visit—the mad rush to remove the dog hair from the couches, the strategic positioning of Sean amidst his toys and the hardest thing of all—preparing myself to appear calm and in control. This pressure begins early. In the early days of Sean's birth I remember feeling that I needed to demonstrate to staff the right mix of grief and acceptance. I felt that I needed to talk to the social worker, nurses and pastoral care worker, not because it was helpful, indeed I was already talked out from dealing with family

and friends but because I wanted to show that I was "coping" and dealing appropriately with the news of my son's disability.

In many situations both dealing with professionals and in the public realm, families endure extensive intrusive questioning and insensitive comments that would be unimaginable in other circumstances. Entering the service world as the mother of a child with disability, means entering a system where you feel scrutinized for your reactions, for your co-operativeness and for your efforts. It means answering questions about what you feed your child, how you discipline your child, how you stimulate your child, how often your child wears his glasses, hearing aids, training pants. It means enduring with humility, even shame, all the "Have you tried...? Have you thought about...? It really is so important that..." questions and admonishments. Again we are reminded that our efforts are never enough. When we succumb to tiredness and have a day where we can't cope with the mess of self-feeding, when we can't bear to struggle with the glasses, where the video machine gets a work out, we mentally prepare ourselves for those questions and we construct the lies we will tell so we don't have to deal with outside judgment as well as our own guilt.

Clare described well the ambivalence that many parents experience about the services they access:

I just can't believe the number of people that we still see, it drives me insane. All of these people have a little part of your life when really they shouldn't be part of my family life. Sometimes I resent the fact that they're even there, that I need them. Although I'm very grateful for them in other ways. You know I just think that everyone shouldn't know what we had for breakfast, lunch and morning tea and that sort of thing, why should I have to keep records of all these sorts of things. the scrutiny:

..... and the physio, you know she's lovely but this sort of guilt and I, I don't know whether it's just me, but I definitely sometimes feel undercurrents, you know "am I really doing enough?" and that sort of thing because Alice's not walking yet. That annoys me. I just want to feel like a normal family, I don't want to be a "special needs" family any more.

Becoming a "special needs family" and the resultant lack of privacy, the scrutiny and the judgments, are the ways parents pay for the services they receive. The common anxiety among parents that they are "not doing enough" seems to be a by-product of the whole experience of being a parent of a child with disability rather than a feeling which is actively encouraged by professionals. It begins I suspect, with the common feelings

of failure or loss of self-esteem encountered following a diagnosis. It is, however, also tied to the subtle ways in which both professionals and family and friends can unknowingly reinforce feelings of failure.

I still feel bitter about the child health nurse who visited and cheerily suggested I "just" needed to feed Sean an extra 150mls per day for "proper" weight gain. He was a baby who would not suck and I was a mother who felt like a milk machine, expressing breast milk at least six times a day. I had recently spent seven weeks sitting in a hospital contemplating the probable death of my new baby and now spent every waking moment planning how to feed this child. Sean was still quite sick, very sleepy, and on oxygen. I fed Sean through a tube two-hourly but he would frequently vomit up any additional milk I attempted to feed him.. Apart from medical appointments I hardly left the house because my routine was so tied to expressing, tube feeding and breastfeeding attempts. It seems of course the most basic job of a mother to feed your child and my own feelings of failure meant that the last thing I was going to do was admit my desperation to this nurse. Instead I outwardly tried to appear excessively compliant as if this might persuade her that I was not to blame.

The reality was that Sean's weight gain while hard won and below the expected gain of average babies, was not so terrible for a baby with Down syndrome. However it took nine months for anyone to suggest that he should be plotted on a weight chart for babies with Down syndrome so this could be confirmed. Until this time I lived with constant anxiety about Sean's weight gain. I think this experience has many parallels in the world of early intervention. While it may be good to have high expectations, this should not cost families the sheer desperation they often feel when their babies and children fail to reach those expectations.

Professionals need to be alert to their own need for concrete evidence of "success". When working with children with disability, their progress must be only one aspect of judging one's efficacy. Again one needs to keep in mind a view of the child as a whole individual within their family. Families may never voice all the additional stresses and demands which they face but you can safely assume that they will be there, no matter how "positive" parents appear. Professionals need to be sensitive to a family's uniqueness, their privacy and their right to make their own decisions. Obviously professionals also need to be alert to parents' vulnerability and the power imbalance at work. They need to be sensitive to the reality that many parents will try to be compliant rather than voice their own opinion, admit their limits or question professional authority. Trying to minimize the "costs" of intervention for families and being non-intrusive and non-judgmental are much appreciated.

Assessment

A great part of early intervention involves an assessment of current skills in order to plan for future intervention. Assessments do not have to be formal and reported in written form to weigh heavily on parents. Every IEP meeting, every therapy review, possibly every therapy session reminds a parent of the child's limitations and how far development lags behind the norm. Many therapists and teachers are highly skilled at focussing on the positives and yet parents often feel sadness, even despair at these meetings. The child with Down syndrome is likely to receive a "room for improvement" report in every area—gross motor, fine motor, speech and communication, attending skills, self-care...the list goes on. This is the case for even the most competent child with Down syndrome. I am certainly not suggesting that therapists stop sharing their expert knowledge with parents or start denying the extent of the developmental barriers, but there is a need for all people who are working with a child to see that child as a whole individual and not a sum of deficits. Don't just tell me that my child can only manage a small number of jumps unassisted on the trampoline—tell me of the joy on his face as he tries. Tell me a lot about the very normal things that toddlers, kindy kids and preschoolers do each day which are greatly beneficial without having a specific outcome or skill development goal. Do not only tell me about the "problems" but show me, if you can, how much you appreciate my child as he is.

Very often the excessive scrutiny of a child's development creates a misleading impression of that child's performance. It can also lead to very inappropriate intervention. A few years back someone who worked with Sean suggested a goal of trying to encourage eye contact and greeting by sign and voice. I had always thought that within the limitations of his lack of speech, Sean was friendly and open and pretty good at greeting people. Nevertheless, this sounded like a fine goal. As time went on it seemed that Sean was actually making less and less effort at greeting people and actively avoided doing so. The worker made greater and greater efforts to engage Sean and eventually was chasing him around the playground, even poking him to get his attention. Her own facial expression and voice were greatly exaggerated and Sean was not at all engaged in the greeting task but very engaged in the avoidance-pursuit game he thought they were playing. The worker's focus on getting him to greet her, had actually led him away from greeting the other children at the centre who were surely the more appropriate focus of this skill development. I observed other children in Sean's group and noticed that many children were highly inconsistent in greeting adults and other children. Some days they would rush up to their teachers and friends and other days they would scarcely acknowledge anyone for a

considerable length of time. These children were not however subject to any of the pressure exerted on Sean. Excessive pressure is likely to be counter-productive and any exaggerated focus on the child with Down syndrome is likely to isolate them from their peers and provide a disincentive for their participation. Even if the child with disability does learn a "skill" which is taught in this way, it does not help them to generalize that skill to relating to their peers.

This is one example from my personal experience but it is hardly exceptional. I can think back to many other situations where Sean has in effect been encouraged to "play" with his adult aide or teacher rather than his friends by the imposition of an adult agenda about what he needs to learn. Sometimes this adult agenda was based on very minimal knowledge of Sean. Nevertheless, learning colours, counting, recognizing letters are all great things. We need to remember though that it is rare that children's developmental impulses will fit our adult timetables. This is one of the great realizations of motherhood. I might put aside half an hour to sit and read with Sean at a time when he wants to do nothing but dress in silly hats. He will, of course, remember the books at dinner time or during an important phonecall. Again the distinction between play and therapy emerges. How little we trust our children with disability to lead with their own interests and the activities which they find intrinsically meaningful and motivating (Goodman, 1996). When I hear research which suggests a lack of motivation or initiative in people with Down syndrome, I am not surprised. If people with Down syndrome have innate difficulties in this area it seems we do them little favour by further disturbing their natural motivations.

Again we must consider the child as just that, a child, with the same need as other children to play and explore and work things out for themselves, even if this is going to be a painfully slow process for us to watch. I am not arguing that there is no place for specific teaching but that this must not be done in a way which pathologizes the child or counteracts that child's acceptance and inclusion. Recognizing that a child's worth is independent of their developmental achievements would surely put some of the goals of early intervention into their proper perspective—as valuable but not "life and death".

Family routine

As mothers we often feel not only responsible for our children's development but their co-operation with early intervention. I remember when Sean was much smaller dreading the fortnightly therapy sessions I attended. Sean was expected to sit in one place for an hour. This is I think unrealistic for any small child but may be particularly unrealistic

for a child whose developmental immaturity means they lack the capacity to attend for lengthy periods of time.

Perhaps the greatest downfall of such a model of early intervention is that it is what parents try to replicate in the home environment. For parents with only one child it is perhaps possible, though I would contend hardly a healthy way to interact with your child. For parents juggling the demands of other children it is a virtual impossibility. The siblings of children with disabilities already experience the impact of parental preoccupation with the child with disability whether it be medical needs, their own grief or the struggle to access appropriate information and resources. It seems unfair that they should also sacrifice a normal family routine. It was, I think, this awareness of my daughter's rights that helped me to actually reclaim some sense of normality, happiness and enjoyment. I became aware that I could just as easily do physio at the park and that I could follow her lead in how to interact with Sean in a way which was not a constant reminder of his inadequacy and my own disappointment in the slow pace of his progress.

Other mothers have also found regaining some balance in family routine a difficult journey:

I don't do as much one on one with Christopher as I used to. I used to when he was the first, say the first eighteen months. There was a lot of therapy, you know one on one with me. I was always going to my older child, "Angus, go away I'm just going to do some work, some therapy with Christopher". But, I don't do so much of that now, I probably do a lot of running around so other people can do it a little bit more for me. Or expose Christopher, I believe in exposing Christopher to as many normal, regular children situations as possible.

I don't get so uptight so much anymore if I don't teach him the alphabet. Because I can't, I just accepted the fact, I used to get upset, thinking "I could do more with him, I could spend hours and hours every day and I could have a genius child". And you kind of could if you had nothing else, someone to feed and clean and wash and you know, make love and do all of that and all you had to do was be a full time therapist. Yeah, but I don't think the real world is like that.

The real world is not like that. Professionals have a role to play in recognizing the "real world" that families live in. I would hope that professionals would not only ensure that they do not place unrealistic demands on families but actively encourage families to remember and value "the things that matter" and to claim their right to a "normal" life.

Denial or Optimism

So often I have heard parents reassure themselves that due to early intervention, the present “breed” of children with Down syndrome are going to be so much better and achieve so much more than past generations of people with Down syndrome. I have also heard many professionals support this idea. While not denying that progress has been made, I am sceptical of this claim. Firstly, I wonder how much of the “improvement” in children with Down syndrome comes from access to proper medical care, involvement in normal family/community activities and not having their potential completely written off. This is certainly an area where early intervention has had a great contribution and has been integral in encouraging parents to see the potential in their children. Nevertheless some of this optimism seems to be a form of denial. People with Down syndrome can be very competent but they do have a disability. I do not think that they should be judged as less valuable for their deviance from normality. In my own journey to understand the meaning of Down syndrome I have found my earlier stereotypes overturned. I am amazed when people suggest plastic surgery (or vitamins!) to reduce the appearance of Down syndrome because to me my son is gorgeous and more generally I find the physical features of Down syndrome attractive, not disturbing. Similarly I see in Sean characteristics which are indeed reflective of the positive stereotypes of people with Down syndrome—an unrestrained joyfulness, a sociability, a warmth which is hard to resist. These and many other wonderful characteristics are what I love about my son, much more than what he is able to do, “how far he has come”. I have also been fortunate to hear the stories of mothers of children with very significant disabilities about how they have creatively sought and achieved quality lives for their sons and daughters and feel confident that Sean’s future does not depend on striving to pass for normal. Sean is perfect as he is and does not need to be improved to contribute greatly to our family and to our circle of friends.

While I am sceptical about this “new breed” of children with Down syndrome, it may be that delaying the parent’s eventual acceptance of the reality of their child’s disability is a useful and positive strategy. As one of my research participants commented she would prefer to be optimistic and disappointed, than to sell her daughter short. It may be that parents are more able to accept the child’s disability when they have had the time to know that child and not just the label. My misgiving is that in talking about the “lucky ones”, “good ones” and “new breed” we devalue the rest. While we must always see that people with disability are also people with ability, we must not confuse competence with value. It seems we are still very much at the beginning of understanding the positive contribution that

people with disability can make to our community and we, as yet, lack the vocabulary to talk about their intrinsic value. This is I believe where much thinking about disability must begin.

Conclusion

In moving people away from a segregated system, our community has put in place a solution to the “problem” of Down syndrome that may be well-meaning but still, we believe, threatens the relationship which develops with families and the community. Children with Down syndrome are “dealt with” in ways that have long since been discarded from regular early childhood programs. Rather than supporting children’s natural growth and development through normal childhood experiences, early intervention programs operate on a “functional, diagnostic” model which prescribes “suitable” activities and governs many early family experiences. While most people these days would not deny the “humanity” of people with a disability, it still seems to be much easier to respond, with therapy, to identified problems and “deficits” than to accept, encourage and support people to be who they are, disability included. We are still, through this system, separating children, and creating the “special needs” family. So much time and effort is put into “readying” the child for the world and so little on actually examining the attitudes of we who make up the world and preparing ourselves for the child. Early intervention certainly has the potential to provide vital support and information to families but no amount of therapy can take away Down syndrome. The most successful examples of children moving into schools repeatedly suggest that a crucial element of this success is the school’s attitude to inclusion; their willingness to adapt and accommodate to suit the child rather than a demand that the child be the same as all the other children. Of course we are not suggesting that children should go unprepared to school but that this needs to always be balanced against what may be damaged if expectations and stress is too high.

As parents we support all our children through the phases of their lives with the inevitable goal that they will one day leave the family and live independently. Even from early childhood the prize of this independence hangs before them and us. In reality, as many people suggest, this is not achievable and we continue through our lives to rely on the assistance of others. For a person with Down syndrome, the goal almost becomes a threat, as independence becomes the prerequisite for inclusion in many experiences. True inclusion only comes with a complete acceptance and appreciation of our fellow human beings. It cannot be a conditional acceptance and cannot embrace some while rejecting others. If we really stopped to think about it and just accepted that it is actually okay to need help sometimes and reciprocally to give it, then

strategies can be set in place that allow a child to actually be a part of life rather than sitting on the outside. Perhaps we are sometimes so hung up on the steps to independence that our children may get stuck, and actually be missing out on experiences while life passes by. Human beings are very creative and resourceful and, I believe, can always find a solution. Once again it is an admirable goal to support and encourage a child to do as much for him or herself as possible, but this should not be a prerequisite for being involved.

People with physical disabilities are often able to advocate for themselves and have described how the intrusion of constant therapy in their childhood damaged their self-image and interfered with their relationship with the world (Mason, 1995). Our sons and daughters with Down syndrome may not be able to verbalise their own experiences with the therapy system, but perhaps they show us this message through the way they grow and relate to others. It is very common to read that children with Down syndrome learn: to avoid participating in learning opportunities, to be helpless, and to react to failure badly. Perhaps they are trying to tell us that, like any child, they needed experiences that celebrated their uniqueness and allowed them to be who they are. Perhaps they needed to play and to just feel the joy of childhood rather than having to deal with therapy situations that we would never expect of our other children. Perhaps neither they nor their parents needed a constant reminder of what they couldn’t do, but rather a lending hand to remember always what they could be.

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Things We Know About Sam

Nancy Barth is a teacher who has responsibility for several students with disabilities. She made up this story to explain to her class why some students “need” different things to help them to be successful in class. It could easily be adapted to fit another child:

After talking to his mom, I whipped out a story, based on incidents that had already happened (wanting his hat, wearing the teacher's bracelet). I read it to the kids after lunch, and we had a nice conversation about becoming a family (a goal of the class in general). We talked about how we each need different things, and when we get what we need, that is being fair. Then the kids started saying the book needed a title, and a dedication, and illustrations (I'm no artist!). I suggested they make those for two copies of the book, one for their class and one for the little boy to take home. One little girl said "I notice he likes my shirt." And another mentioned something else, so I suggested they add a page that says, "Things we Know about ____."

Their teachers suggested they could also make books about themselves for the class to share. They are such thoughtful teachers!!! Taking something that singles him out, and making it into something the whole class does. I love this part of the job!

Once there was a little boy named Sam.

Sam looked just like all the other kids.

He liked to play outside.

He liked to read books.

He liked to use the computer.

But Sam was a little bit different.

The doctor said Sam was autistic.

The kids said, "What's that?"

The teacher said it meant that Sam needed to do some things in a different way.

Sam liked to wear his Mickey Mouse hat.

Some of the other kids wanted to wear hats, too.

But Sam needed his hat to feel safe, and they didn't.

So his teacher said that Sam could wear his hat to school.

Sam had a hard time sitting still to listen to a story.

He wanted to move around.

The teacher gave Sam a bracelet to hold, and Sam sat down and listened.

Some of the other kids wanted bracelets, too.

But Sam needed the bracelet to help him pay attention, and they didn't.

So his teacher said that Sam could hold the bracelet.

Sam liked to repeat words and sounds when he heard them.

Some of the other kids wanted to know why he did that.

The teacher said that it helped Sam to learn new things.

Sam sometimes had a hard time changing from one thing to another.

So Sam had a special person who helped him with the changes.

Some of the other kids wanted to know why he was the only one who had a special person.

But Sam needed the special person, and they didn't.

Sam was autistic, and he did some things a little differently than the other kids.

But mostly, Sam was just a little kid like they were.

*Reprinted with the permission of the author, Nancy Barth,
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