

The Impact of Inclusion on Children's Lives: multiple outcomes, and friendship in particular

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ABSTRACT *This paper describes the work of a Consortium for Collaborative Research on the Social Relationships of Children and Youth with Diverse Abilities. The Consortium was a 5 year research institute funded by the US Department of Education, carrying out research in the Los Angeles, San Francisco, and Sacramento areas of California; the Seattle and rural-suburban regions of Washington State; New York State including New York City, Syracuse and rural regions; and Maryland. The work was undertaken in rural, urban, and suburban school districts, with a demographically diverse population, and also directly with families. This paper shares the results of research findings on children's social lives in inclusive settings, while weaving a theme throughout the presentation of how this research was done. The focus was upon the role research should play and was directed toward closing the gap between research and practice.*

The Purpose of Research

I am assuming that any research is intended to generate socially useful knowledge. The research we do is meant to be useful, is meant to be applied—we are educators and psychologists who work in applied fields, so we are interested in what happens with the work that we do. In particular, I assume that educational research is supposed to make a difference, and the research we do should improve practice. The sober reality is that, despite such intentions, there is a huge gap between research and practice. Typically, practitioners are blamed for this reality. I think that the problem starts with the kind of research that we do. In the Consortium, we had to learn new approaches for our research on children's social lives. This was a perilous journey, a very difficult journey, requiring a great deal of personal and professional growth. It wasn't easy. I think you will see why, when I give some examples of what we did. But it is what we have to do if we are going to close the gap between research and practice.

We were very fortunate to have significant research funding to answer particular

research questions about the impact of school and community practices on children. In the United States a major policy decision had been made that children with disabilities would be included in school, community, and work sites throughout their lifespan. No one really knew, though, what the consequences of that decision were. It is important to realise that the decision to include children with disabilities in their communities is not an empirical question—it is a social value. A values-based decision had been made. Nevertheless, we as educators, and as researchers, now must take on the responsibility of ensuring that the children are going to benefit from that social decision. If we learn that initial results might be negative, this does not mean we abandon the social value of inclusion. Disappointing results *do* mean we need to work hard to improve practice, so that we can ensure benefits for the children involved. Making this commitment could be a very long and involved process.

Research Question: The Impact of Inclusion on Children

The researchers set out to answer this research question: What is the impact of inclusion on the children? To answer this question, we looked at children with severe disabilities as well as children who did not have disabilities, their nondisabled classmates. We evaluated the impact of inclusion and the merging of special education and general education into a more unified system on all of these children with diverse abilities and their programs, including the resource implications and the changes impacting on general education as well as special education.

As educational researchers, we were influenced by some serious concerns about the research process itself. First of all, who decides what question to ask? We were given a question when we responded to the US Government's "Request for Proposals" on this issue—we were told to look at the nature of social interactions and the outcomes for the children involved in inclusive programs. But how we approached this—the specific research questions we posed—was something we needed to address.

We were going to design interventions and presumably "interventions" means people are going to do something—someone is going to change behaviour. Typically, many of our interventions for children with disabilities have focussed on children doing the changing. That is fair enough—surely this is why they are in school—and sometimes when they do not progress adequately, we say inclusion does not work because children have not changed enough. We may say the reason it is not working is because children are not yet ready. It seems to me that it is the adults who cannot seem to get ready, so children spend an entire lifetime—another entire generation—waiting until everyone is ready for them. Then, of course, they miss their chance because they grow up.

How then did we design the intervention? There is extensive research literature on how to develop interventions that do change behaviour, but many of those interventions are developed in isolation from context and in isolation from actual environments. Questions for the research process continue: How are data collected, and by

whom? Who interprets the findings? Who decides the value of our outcome? In our research literature, we have an historical belief that there are clear, rational ways of making these kinds of research decisions.

The Role of the Researcher

We have a profound belief that the research process is objective, pure, fair, uninfluenced by personal bias, honest, open—all of those good things. Brew (1999) discusses this interesting phenomenon of our belief in objective, rational, and reproducible results, noting with interest that all of the difficulties and the doubts of doing the research are forgotten by the time it makes it into the journals. One of the things that fascinated us is the dominant paradigm of social science as an objective endeavor. This paradigm assumes that the researcher comes to the process with no bias, no prejudice, no preconceived notions, no lens with which to view the phenomenon but actually has what Greene (1996) called a “view from nowhere.” If bias exists, the researcher can set bias aside during the research endeavour. We would have to question whether it is actually possible to ignore all personal influences and personal opinions when we carry out research.

We were supposed to study children's friendships—children's social relationships—and I would be the last person to claim that any of us as researchers had a view from nowhere. On the contrary, we considered that our perspective, as adult researchers, might be a distinct disadvantage in studying children's friendships and children's social relationships. Each of us obviously had a situated vantage point, in our case, including perspectives as adults, as women, as university academics and as researchers—as well as our individual identities arising from cultural background and life experiences. Any researcher has a situated vantage point and any participant in the research process also has a situated vantage point. One of the interesting things about research is that researchers are coming to acknowledge that we are influenced by our own repertoire, our own beliefs, our own previous knowledge—everything we bring to that research process helps to form the lens through which we look at the phenomenon.

So we are influenced by our personal beliefs, our personal status, the fact that we are academics at a university or research assistants in a laboratory, our academic discipline, whether we are psychologists or educators—all of those things influence the way we “see” things. A psychologist might tend to see all the interpersonal factors, a social worker will see environmental circumstances, an educator will see skills, and so on. However, the research literature is generally silent about the culture of the researcher and the researched; we have a literature that has actually been framed by one segment of the population, primarily by white and middle class researchers. Further, we have looked at only one segment of the population. Particularly in disability studies, the vast majority of the research is about white children, European children, not culturally diverse children. Alternatively, often nothing is said about certain demographics beyond age and gender, so that the literature is silent on culture.

Participatory Research toward Better Understandings

Our research team decided from the beginning that it was crucial to use a paradigm called participatory research. Participatory research is multi-method, or can adhere to a particular method. In our case, we pursued a number of alternative research methods to address different aspects of the overall theme. A critical aspect of participatory research is that it acknowledges the situated vantage point of all of the participants in the research process. We decided it was important to do that, because if we were trying to understand children's friendships the fact that we were adults was a significant disadvantage. How would we really be able to make meaning out of children's friendships from our perspective as adults? How could we not professionalise what we saw? And in fact if you think about the literature on helping children make friends, what is the most prominent model we have? It is a peer tutoring model, or a "special friends" model. If you peel away the layers of what such models are all about, they are really "professionalised" models where a teaching role or dominant role has been assigned to one child and a subservient role to the other child. Is that how children make friends in natural circumstances?

It may also be that if one's personal perspective is monocultural and gender specific, the ability to understand the dynamics of diverse populations of children is compromised by that perspective. This research team included a very culturally diverse group of people, however, we are not suggesting that the way to solve this issue is to have African Caribbean researchers work with African Caribbean children, Maori researchers work with Maori children, and so on. While this kind of "matching" might indeed improve the probability that the researcher will better understand one dimension of those children's lives, it ignores the dynamics of many other dimensions on which researchers and children differ. Even if we could, in fact, match culturally, it would be impossible to match on all these other variables that might have an impact on our understandings of our findings. In this project we adapted a participatory research process which, according to Turnbull and others, is well-suited to these kinds of research questions because it involves the collaboration of community and family, service providers, theorists, and researchers working together (Turnbull, Friesen, & Ramirez, 1998). Such a model sees research as a means of enhancing best practices, rather than an end. Participatory research assumes that research is the enterprise of not only scientists but also consumers of research—family, community, service providers, and even the children themselves. Participatory research is an attempt to combine scientific knowledge and experiential knowledge to enhance quality outcomes for the community. Some of the best examples of combining the agendas of research method, educational improvement and social action have been carried out in Latin America (Torres, 1995). This work has its origins in the writings of Paulo Freire (1985).

We were also greatly influenced by the theoretical writings of Habermas (Ewert, 1991) and the more practical concerns expressed by researchers such as Hoshmond and Polkinghorne (1992), Delgado-Gaitan (1993), and Cousins and Earl (1992) regarding the relevance and usability of research. It seemed that if research were to have an impact on practice, we needed to utilise alternative methodologies appropri-

ate for different aspects of the issues, and we needed to examine how those different methods fit together to give us a more complete picture of the phenomenon. We were very conscious of the paradigm war situation that had evolved in certain circles between qualitative and quantitative researchers, who seemed to spend a great deal of time arguing with one another, putting one another down, and/or justifying why their particular approach was superior. Rather than assuming that one or the other methodology has found the truth and the light—representing the *correct* way to do research well—it helps to read someone like Habermas who explains why we need different research approaches suited to different issues and different questions. Clearly, our research questions required the use of different approaches if we were going to uncover any meanings about children's social relationships that would make sense for the design of interventions.

Multi-Method Research for Application for Improved Practice

In Habermas' model, there is technical knowledge—you could call that empirical analytic or quantitative knowledge. Technical knowledge can provide empirical support for observable changes in behaviour associated with one another. This is an approach to research initially validated in agricultural science early in the 20th Century, evolving into our experimental designs for research, whether for individuals (single-subject, time series) or groups (nomothetic comparisons). A second type of knowledge is practical knowledge which could be called interpretative or qualitative knowledge. Such knowledge can also provide empirical evidence for behaviour change, but the emphasis might be on how meaningful something is. After all, we could achieve one full standard deviation of behaviour change on a particular measure, and the family could still tell us that the test score does not matter to them. Knowing that a child does something five times a week or ten times a week, does not answer the question of whether either is meaningful. Qualitative findings—interpretations of those numbers—are necessary to indicate whether the behaviour change is meaningful. Thirdly, reflective knowledge describes the process of taking a social value—a social decision that has been made, like inclusion—and developing interventions that will make the social decision a reality and turn a value into practice. A critical component of our research on inclusion is to carry out what Habermas called emancipatory research. Carr and Kemmis (1986) called it critical theory, Robinson (1993) called it problem-based methodology. In each model, we ask people to accept a challenge of change, and make it happen—make it work.

So when we designed our research on children's social interaction we realised that we needed to do all three types of research, and to incorporate a participatory research approach where appropriate into the conduct of each of the three methodologies.

Outcomes of Inclusion for Children and Youth

Why, after all these years of inclusion internationally, is there no longitudinal comparison research focussed on how children have done in inclusive vs self-con-

tained special education programs? In the early 1990s we published a research report on different outcomes for children attending integrated (not inclusive) vs segregated schools (Cole & Meyer, 1991); as yet there has been no other longitudinal research on different measures of child performance by placement for children with severe disabilities. Longitudinal research of this kind is rare because it is difficult and expensive to do, and it may not be possible without significant additional research support such as we had. Given the substantial research resources awarded to the Consortium, carrying out such a longitudinal comparison was one of our responsibilities.

Comparing Progress over Time

The Consortium undertook to report a longitudinal comparison of outcomes for matched students who were attending either inclusive or segregated, self-contained special education programs. It took us 5 years to match 20 pairs of children with very severe disabilities by age and their pretest assessment scores on psychometrically validated measures of development and social competence. Because the study focussed only on children and youth with severe disabilities—a very low incidence population to begin with—making matches by chronological age and pre-test assessments was challenging and time-consuming. Considerable data loss in the sample was also experienced. This was due to, for example, extended absences at the time of the end-of-year assessments (resulting in a missing data-point) or a child dropping out of the sample by moving away; either of these scenarios required a new match for another child to make a pair. We collected data for literally hundreds of students over the 5 year period so that, in the end, we were able to match 20 pairs (40 children in all) for a reasonable comparison across two years. We could do comparisons for smaller numbers of matched pairs across three and even four years, but we had a sufficient sample size for the planned statistical analyses for only the two-year comparison. At the first assessment the pairs of students—one in a segregated and the other in an inclusive program—were sufficiently matched so as to provide a reasonable test of two years of the impact of one placement or the other. Children and youth in the sample ranged in age from slightly younger than 6 years to slightly older than 19 years of age, and the sample attended schools primarily in different regions of New York with some in California and Washington states.

As noted earlier inclusion is not an empirical question. It is a question of values regarding what we want for our children, their families, and our schools. But having said that, it might be important to do comparative research to ensure that this values-based decision is not actually doing harm to the children involved. It might also be important to evaluate any new program direction so that if problems are revealed, we are aware of those shortcomings and can undertake program improvements to address difficulties. Our hypothesis was that the two groups of children would achieve, overall, similar gains across the two year period on the two assessments. It seemed to us that the segregated sample would have to achieve far superior results in order to challenge the social decision promoting inclusive programs. Clearly, if our inclusive programs did not reveal positive outcomes for children, we

must find out why and determine how to improve the situation. That, at least, was our *opinion* as researchers. Participatory research requires that we share research outcomes with the constituents of that research (e.g., children, parents, policy makers, teachers, and many others who are stakeholders in the process) and find out what *they* think about our findings.

How well then did our students do, according to the measures used in our study? As a group, the inclusive students outperformed the segregated students, achieving statistically significantly higher scores on the post-test measures (Fisher & Meyer, 2000). However, this was not the case for all the individual children. There were several children in each group who made no progress or regressed on both measures, and nearly half of the children overall made no progress or achieved lower scores at post-test on at least one of the measures. Our stakeholders agreed it was meaningful that, overall, the inclusive students did better. They regarded these findings as providing strong evidence that they could use to persuade others to make the investment of time, funding, and professional expertise to develop further inclusive programs for children. That is, even though they themselves might favour inclusion, stakeholders who do not favour inclusion might be convinced to reconsider their beliefs based upon strong evidence that it is good for children. But parents and teachers were also concerned about the individual children in both groups who actually scored lower at follow-up. Indeed, identifying these children, developing hypotheses for their lack of progress, and designing new interventions to improve their learning should be the next focus of our work. The same things might not be working for everybody—is that not the underlying assumption behind individualised programs?—so we must figure out what the issues are for individual children. Subsequently, we have provided detailed case studies for some of these students in order to provide information on what might have gone wrong along with examples of things that were successful (Grenot-Scheyer, Fisher, & Staub, 2001). The research literature generally reports only the successes, but we believe that we can also learn from the “failures.” Discussing our limitations as well as our successes in rich detail can help other educators and parents who might be struggling with some of these same issues.

Note then that our research approach accommodated the need for different kinds of information or answers. For those who want statistical, empirical evidence on outcomes for children, such information has been reported across two years of programming. But we have also looked at these data more reflectively, with specific interest, to understand better why different children experienced different outcomes. We were particularly interested in and concerned about those students who failed to benefit from inclusion. These children might have failed to progress regardless of their program type, but we will never know that. What we do know is what their programs were like and what we can do is make various changes to those programs—then evaluate our efforts to improve the situation. It was also particularly important that we look at other “outcomes” for children in our sample, as we know that some children do not, in fact, show demonstrable gains over time on such measures despite testimony from their families and teachers that there had been major and meaningful outcomes (see e.g., Evans & Meyer, in press). Thus, we were

interested in looking at the nature of children's social relationships and their friendships as well as doing group comparisons on social competence or developmental measures.

Looking Closely at Friendships and Social Relationships

In another study, we asked 6- to 9-year-old children in general education classrooms that included one or two children with severe disabilities to nominate other children as best friend, regular friend, a work buddy, a non-school companion outside of school, or as someone who would be invited to a party and so on (Meyer, Minondo, Fisher, Grenot-Scheyer, & Larson, 1997). We found, for example, that on average, a child with severe disabilities received 1.75 nominations as a best friend, whereas a nondisabled child received 2.1 nominations as a best friend from their classmates enrolled in inclusive programs. The nondisabled child got slightly more nominations on average, but this difference was not statistically significant. A statistical analysis cannot tell us, however, whether a child and/or the parents might value the fact that the child with severe disabilities was indeed named as best friend by 1.75 other children! It might be that being named at all would be an entirely new and highly valued outcome for parents and for the children themselves. And the difference between 1.75 and 2.1 might not be meaningful to the parents. When we described these data to groups of teachers and parents, they were universally impressed with what they saw as very similar social outcomes for these two very, very different "groups" of children. Our participants told us that this outcome meant to them that inclusion was working.

Thus, the quantitative evidence required a further look through a series of qualitative studies. We needed to look at the social exchange data we had, have our observers comment on them, have peers comment, have teachers evaluate the results we obtained, speak with the families and so on. Social validation of our results was needed and some of our results are outlined below.

Frames of Friendship: Children's Social Experiences

There is rich theory about the different social relationships that people experience. Fiske (1992) describes four social relationship types that seemed to have some utility for understanding interpersonal expectations for all children—we were looking for theory that encompasses both children with disabilities and nondisabled children, rather than assuming that there should be something very specific, only to children with disabilities. We began with some very general ideas only from Fiske's (1992) work and were able, based on our observational data as well as survey and interview data, to document what we called "Frames of Friendship" (Meyer, Minondo et al., 1998). There are six of these Frames of Friendship that existed for all of the children that we were observing—typical children and children with severe disabilities alike. They are: (a) Best Friend, (b) Regular Friend, (c) Just Another Child, (d) I'll Help, (e) Inclusion Child, and (f) Ghost or Guest. Typically, we all experience these six Frames of Friendship in different circumstances and with different people—all

are appropriate depending upon the circumstances and there should be a certain balance across the frames. Difficulties arise when a child's social experiences all fall within certain frames that exclude positive social relationships and friendships with peers, as would happen if a child with severe disabilities experienced only being helped or ignored in an inclusive classroom, but never had a best or regular friend. In our meetings with parents and educators as part of our participatory research process, we were able to validate the relative valuing of the frames—the fact that each could be appropriate in certain circumstances, and the expected balance rather than imbalance across the frames as the desirable goal.

Just to give a little idea of what the frames mean for children, let's take the Frame "Ghost/Guest" (Black, 1996). This is somebody who is like a visitor. There are times in our lives when we are all visitors, when we are ignored, and when we are expected to be like "ghosts" in an environment or situation. The social status of a guest is like relatives who come to visit. You are really pleased to have them for the first few days, and then after about a week you might wonder when they are leaving—they were not meant to live with you permanently, but are guests. We found schools and classrooms where the first reaction to a challenge with a child with severe disabilities is that everybody starts talking about "the classroom over there where that child's needs could be met so much better." It's a bit like a parent saying "Ah, Johnny really has been difficult this week—I think I'm going to go out and find another mother and father for him who can better meet his needs." When there is a problem and the person is truly part of the social network, the problem requires solving without the option of getting rid of the person. If, on the other hand, the person continues to be seen as a kind of visitor, this attitude reveals itself in problem situations where the first reaction of the "insiders" is to suggest that a problem be solved by excluding the "outsiders." For example, this can occur for children who are accepted in the classroom as long as their behaviour follows certain agreed norms and who will quickly be suspended or expelled once behaviour exceeds those norms. What messages are being given to children when we are so very quick to send them away if the job is not easy?

There are, of course, times when it is appropriate to be a guest or even to be a ghost, but we did observe some "inclusive" classrooms where everyone in the room just went about his/her business as if the child with severe disabilities did not exist and was not there. Parents and teachers all agreed that if this situation described a child's entire school day, it was a problem. How did such a situation develop? While we could probably never determine the cause, we could see a lot of things that adults were doing that probably contributed directly to a child's isolation over time. For example, parents might tell their children not to stare at somebody with disabilities in the grocery store which, for young children, is like pretending that the person is not there. Presumably, one is trying to avoid discomfort and embarrassment, but what might be happening is that children are being trained to ignore one another—certainly, to ignore a child with disabilities. It would be far more natural for a child to initiate an interaction, to ask the child with disabilities what he/she is doing or why he/she is using a communication board.

There was another frame we called "Just Another Student" that was most

appropriate for many social situations. Children in the classroom were all members of the group, and during a truly inclusive lesson that involved watching or listening to something, everyone would look like each other rather than standing out by doing something very different other than watching or listening.

Parents and teachers were ambivalent about the “Inclusion Child” frame. Generally, adults want at least some form of what we labelled differential treatment for the student with severe disabilities (that belief is reflected in the entitlement to an Individualised Educational Plan or IEP). Evidence of overprotection was not uncommon; special treatment was reflected in exceptions to rules other children had to follow, and there were different expectations not only for performance but even for participation. On the one hand, policy supports inclusion, but in practice, inclusion can entail a day-to-day program that is actually very different from what classmates are doing. While this may be temporary, making exceptions in comparison to age peers may be doing some damage—we may be creating a special status which is not the same as being a friend and may actually be interfering with the development of social networks with peers. The status of being the Inclusion Child was evidenced by interpersonal behaviours between children that were quite different from typical peer interactions. For example, young primary age children could sometimes be heard talking in “baby talk” or “like a teacher” to the classmate with severe disabilities. These children seemed to be imitating how they heard adults talk to that child—also observed in our data—so an important and natural intervention is to work on those verbal behaviours. On some occasions, it almost looked as if the nondisabled child was playing with a pet; both teachers and parents agreed that extreme examples such as this were not a desirable social experience for either child.

The “I’ll Help” frame was predominant in the social lives of some children who were always being helped by peers, but never expected to help anyone else. Teachers sometimes inadvertently encouraged permanent labelling of a child as someone that everyone else helps. We urged teachers to stop a fairly common “inclusive classroom” practice of posting a list in the room for the children regarding whose turn it was each day to push “Johnny’s” wheelchair. We asked teachers to be more aware of how they talked about—and how the children themselves talked about—interactions with classmates who had severe disabilities. If children continually describe those interactions as “working with” and “helping” the child with disabilities, what would otherwise be normalised helping situations turn into a hierarchical social status among children.

In our friendship survey, which was described earlier, children did select certain friends because those other children helped them. But we found almost no examples where a child with severe disabilities was named as a friend for helping someone else. They could help, of course, there is really no reason why every child could not be expected to help others. But very often, children with severe disabilities are not expected to help anybody else. We considered that a great deal of attitude change had to occur in order to have a more normalised social status among children.

There were mixed feelings about the I’ll Help frame. Parents of children with severe disabilities liked the fact that other children helped their children—for some, this was seen as a major benefit of and reason for inclusion. Other parents involved

in our family studies felt very, very strongly that they wanted their children to be treated just like anybody else. All of us in various environments will be just like anybody else. We are meant to blend in, be part of that environment, we are not supposed to stand out. Blending in does not always mean being left out, but rather that one is like everyone else and not the centre of attention. In some environments and situations, one is expected to meet the same performance expectations as others, and consequences for not doing so should be the same. The issues of expectations and consequences provoked a great deal of discussion and controversy among adults and children alike.

“Regular Friends” and “Best Friends” are the final Frames of Friendship. Everyone who participated in our research affirmed that both of these frames were natural and desirable social relationships. “Regular friends” was a phrase teenagers used for peers who were not best friends but were just friends. Regular friends would be invited to a big party, not for an overnight stay. A regular friend was not the person you would talk to on the telephone two or three times a week or have over to your house after school. Regular friends would talk to one another in the lunchroom and spend time together after school. We all have different friends for different occasions. Some people we go to the movies with, and others are the ones we phone to travel together to an evening meeting that involves both of us. We each have a circle of acquaintances with whom we spend time. Best friends, however, are “friends forever”—as teenagers sometimes called them. The literature on children’s social relationships suggests that having a best friend is critical, but is generally silent on the issue of regular friends. We were sensitised to the importance of both types of friends. Outcomes such as friendships are another example of our social values. Everyone could benefit from having at least one best friend. Whether or not having friends is a good idea is another example of something that is really not an empirical question. Research is not needed to answer that question.

Well-developed social lives include all six Frames of Friendship, with different social interactions and relationships occurring at different times, in different situations, with different people, and even with the same people but varying for different circumstances. There will be times and places in your life—on the very same day—when you are being helped or, alternatively, helping someone else. You may be like the Inclusion Person. For example, you may be the last person in your workplace to enrol in a particular professional development session; temporarily, you become the special person learning new information technology skills in that environment. While learning, you get extra attention but only temporarily. Once you have learned the skills, you will be like everyone else at the workplace. There will also be times when you are a Ghost or Guest. And the movie about Crocodile Dundee provides an excellent example of when one should be Just Another Person. Remember when the main character tries to say hello to everybody in New York City while walking down the street? The scene is funny because we know that the usual rules for social interaction with others are to ignore passers-by—that it would be impossible to try to say hello to everyone in this kind of impersonal situation. There are times when we know our role is to blend in. One of the challenges for persons with disabilities in competitive employment can be learning *not* to greet

everybody. There are times when social interaction rules mean one does not interact actively, and socially-skilled people know the rules for when that is expected. Finally, there are different kinds of friendships. Sometimes these relationships fit the category of regular friends and each of us wants to have at least a few of those for a well-balanced social life. And we each certainly want to have one or two best friends, virtually everybody would agree with that.

Social Status Patterns: An Example

Not everyone believes that a child with disabilities can have either regular or best friends who do not have disabilities. In our research, we did find children who had neither, but we found other children who were almost “developmental twins” who did have regular and best friends. What is most important is that there seemed to be patterns of adult behaviour associated with the absence or presence of this social dimension in children’s lives—suggesting that intervention is needed to support those patterns associated with the development of friendships in the lives of children with severe disabilities. Matthew’s pattern of social relationships serves as an example of a social status pattern that was unbalanced, with no evidence in our observational or interview data that he had any regular or best friends. While everyone agreed this was undesirable, not everyone agreed that anything could be done about it—Matthew’s disabilities were said to be too severe. This seemed to be the final attitudinal barrier to inclusion! Some examples from Matthew’s data, as well as other children’s data, illustrate how the absence of friends appears to be associated with certain patterns of practice that could, in fact, be changed through intervention, creating a more balanced social status for Matthew. We believe this is possible precisely because we were able to show—for other children whose disabilities were just as significant as Matthew’s—that friendships did occur, and were clearly associated with very different (facilitative) behaviours on the part of parents and teachers (Evans & Meyer, in press).

Matthew is a student with significant disabilities who was 14 years old at the time these data were collected. He attended what his school district regarded as an inclusive middle school program, but based upon his actual educational experiences we regarded it as integrated. Matthew was not, in fact, included, as he spent most of his day being pulled out of general education classrooms into a special classroom. Our data included continuous observation days that were randomly selected, where we followed Matthew for the entire school day (Meyer, Minondo et al., 1998). As our observers had already been in the school for weeks and months and were very familiar to everyone in the school by the time these observations were conducted, they could follow the students around with little notice being taken by adults or children. Part of our participatory approach involved using observers who were people from the community rather than the more traditional “graduate student observers.” Because our observers were part of each particular community, they were in an excellent position to interpret everything that was happening, and they were regularly consulted by the research team to solicit their input in interpreting findings. They were well trained and our observation procedures met rigorous

standards for observational data collection (see Biklen & Larson, 1998, for more information).

Matthew's total social life was comprised of the four frames I'll Help, Inclusion Student, Ghost or Guest, and Just Another Student. Matthew's relationships with other children resembled what Green and Schleien (1991) referred to as "facades of friendship." He had no regular friends, and he had no best friends—none that we observed and none reported by the adults in his life. In contrast, he spent lots of time being the Inclusion Student—literally hundreds of children would say hello to Matthew in the school corridor between classes, but nobody would talk to him at lunchtime beyond a social greeting. He was the "I'll Help" student a lot; other students (and adults) would push his wheelchair, but not talk to him even while they were doing that. He was often a Ghost or Guest and, occasionally, he was Just Another Student. Was this a good outcome for Matthew? Was this what we were thinking of when designing inclusive programs?

When we shared these data with focus groups, everyone agreed that it would be preferable to have a different pattern that included friends. And one of the researchers (this author) could have said "I think what we have to do to train Matthew to have best friends is ..." and then designed a special program to make sure that happened. But in this research model this is not the decision of an individual researcher. Nor was it the teachers' decision how to help Matthew make friends or how to intervene with all the children in the school. We first needed to find out what Matthew wanted and what his family saw as a goal. We needed the other students to tell us what was going on in that situation. We needed to understand more of what was happening in that school environment. And if Matthew was unable to speak for himself—and he was not able to do so—we followed a procedure that seemed the best way to find out what was natural for a 14-year-old. This involved asking other 14-year-old students what *they* would like. So a small group of 14-year-olds, members of a focus group, was asked what they thought ought to be done. In order to support friendships for Matthew, we might have designed all sorts of elaborate interventions. Instead, we needed to design naturalistic interventions—interventions that work very naturally in real world environments. Further, there was evidence that our own behaviours and messages—as adults—may be having devastating and unforeseen consequences for students like Matthew despite our best intentions. The next section includes some provocative evidence that this is so, based on what the students themselves told us.

Adult Messages and Behavioural Consequences

The following section shows that, even though we are not intending to intervene, we may be carrying out some quite devastating interventions. The quotes below are from a focus group of teenagers in Brooklyn who were in classes with children who had severe disabilities. The teachers in this particular school referred to their program as inclusive, but again, the actual educational practices were integrated and not inclusive. The interviewer is a young, former teacher from Brooklyn who was

selected for this role because she related well to the students. Here is what we recorded in one of those focus group meetings:

- Interviewer: Are Sam and Karina friends like other friends that you have?
 S: Not quite like them.
 Interviewer: So how is it different?
 V: It's hard to explain.
 Interviewer: What do you think?
 T: They're not around all the time.
 Interviewer: What do you mean they're not around all the time?
 T: Like, you wouldn't actually see them all day. They're not in all your classes so you don't usually see them all day.
 Interviewer: So do you think that it would help Sam and Karina to make friends if they were in classes more often?
 T: No, 'cause they could have friends, it's just that what's different is that you don't see them every day, and they don't actually come to your house, so they're not around all the time.

What the student is referring to is the fact that the students with disabilities were not attending their neighbourhood school as were their typical classmates. The other students could get together after school, but because the students with disabilities did not live close by, they were not "around all the time." The students with disabilities were transported by bus to the particular integrated school from various neighbourhoods, so that almost none of them happened to live in the same neighbourhood as their classmates.

- Interviewer: What do you think, C?
 C: The question is that if they didn't have friends, they don't have to be in our class to have friends, but I know Sam and Karina, [names three other students from the self-contained class] or whoever, they come into their own classes, they have their own classes, they teach them, they go to the room next door, they're in a group, so if I'm Sam and she's Karina, I would be her friend because we're in a group and we're together and we often see each other.

What they are talking about is the pull-out special education class. They are saying students with disabilities "are OK," they have friends, they have their "Special Ed" class.

- Interviewer: What do you guys think? Anybody else think [the students with disabilities] could be like a best friend to somebody? To one of you guys or to somebody else?
 C: The definition of a best friend is, you do not laugh when they make fun of you, you do not make fun of them or any relative, you behave to their relatives and yours, a best friend is that you could share things

with them, you could tell them secrets that they would not tell anyone. That's the definition of a best friend, but I think we could be Sam's friend, because a friend is a friend, you talk with them, you laugh with them, you don't make fun of them.

Interviewer: You ever make fun of any of your friends?

V: Sometimes. You could play around.

C: I be [sic] annoying to them.

Interviewer: So you could tease them?

T: Yeah, like if they like a boy and the boy doesn't like them, you could tease them about it.

C: Yeah, but they [the students with disabilities] won't understand. Your friend would understand what [sic] they tease you, making fun of you for real or are they just playing around.

Interviewer: So you think you could be friends with Sam and Karina, but you don't think you could be best friends with them? What do you think, S., could you be friends with them? And then what is a friend compared to a best friend to you? Is there a difference?

S: Yeah, you could have a friend that's sort of friendly but then you know you could see her every day, and sometimes they come over [to] your house, and you know you could play around with each other, you do stuff together. A best friend is the one you could talk to if you have like a problem or, I don't know, you could share things with.

Interviewer: So all of you, I'm going to ask you a question, you answer yes or no. Do you consider Sam and Karina your friends?

T: If they're not best friends, then they're friends.

Interviewer: So do you have friends that you would call up on the telephone and talk to? So what do you think, T?

T: I think they could be best friends and call them or whatever if they could use the phone, or if they had their phone numbers. But the only difference is that you can't really make fun of them, because they're disabled and you shouldn't make fun of a disabled person.

Students told us over and over again that it was not nice to tease children with disabilities. What are the consequences of this message if part of being a teenager is teasing—and learning the “rules” for fun teasing vs bullying—but teenagers with disabilities are excluded from this very significant part of teenage social behaviour? And how will young people with disabilities develop a sense of humour if they cannot experience opportunities to be part of these interactions?

A Model of Four Intervention Approaches to Support Social Relationships

We were able to identify four variables associated with various patterns of children's social relationships.

The Child's Repertoire. This may be the most obvious, but rather than assuming that students simply needed to learn social skills, good decisions must be made about priorities for changes in children's repertoires rather than teaching students behaviours that make little difference in social interactions. It is also important that educational goals are valued by the child's family and cultural context, or the skills mastered will not be maintained or even useful outside the classroom.

The Social Ecology. Various dimensions of the environment or setting were associated with different patterns of peer interactions. Classrooms that accommodate diversity and do not stigmatise students with severe disabilities (e.g., through different activities, different seating arrangements, and even different expectations for following classroom procedures) provide the context for friendships between children. Classrooms that stigmatise children with disabilities through constant reminders that they are different are associated with restricted social relationships for those children as their peers pick up signals from the environment to treat them differently.

Adult Mediation. How teachers, teacher aides, job coaches, and other paid caregivers performed their support role could result in facilitated, blocked, or missed opportunities for social interactions. The teacher aide who is "velcroed at the hip" to the child clearly blocked—prevented—the child with disabilities from most day-to-day peer interactions and thus opportunities to develop friendships.

Peer Skills, Support, and Expectations. It is important that children without disabilities be provided with information and support needed so that they can interact positively with peers with severe disabilities. They may need to understand how a communication board works, or may need to be encouraged to speak directly to their classmate with disabilities rather than talking through the teacher aide. They should experience mutually beneficial interactions with peers with disabilities, rather than always being asked to help or "work with" those classmates.

It is interesting that the variable of "child repertoire" receives almost all of our attention, especially the training of social skills. Obviously someone's social repertoire influences their social relationship outcomes. But the social ecology has an important impact, such as the structure of the classroom, where the child sits, expectations for performance and participation, and all the other dimensions of the classroom environment.

Similarly, peer skills, support, and expectations make a tremendous difference. Do the other students know how to use the communication board that Matthew has? Do they know how to put on the brake on his wheelchair? Do they expect Matthew to communicate with them or do they expect to ignore him? Do they think it's acceptable to tease Matthew, just as they tease one another?

Finally, adult mediation plays a major role. How do the adults act, interact, prevent, facilitate, respond? Adult mediation does not necessarily involve teaching adults to do lots of different things, but may instead involve teaching adults to

restrain themselves so that they do not interrupt or interfere with natural peer interactions.

Two examples from our observational data and some comments from the children themselves illustrate the influence of adults on peer social interactions and relationships. Adult mediation was an important focus of our efforts to develop interventions, as adults do have critical roles and responsibilities in educational programs. Typically, some level of direct support in the classroom from a teacher aide, teaching assistant, or paraprofessional (the specific terms vary) is the one service that every student with severe disabilities will receive. Yet, just as universally, they are probably the least trained person on the educational team—they are seldom given any specialised training at either preservice or inservice level, and are even selected primarily for personality variables or because they have been in a school in a variety of roles for a long period of time (Minondo, Meyer, & Xin, in press). Everyone just assumes or wants to believe that we know what to do. We do not help them very much, we do not prepare them, and they may even be assigned to the same child year after year.

Adult mediation encompasses any behaviour by an adult that could have an effect on the interaction between a student with disabilities and a nondisabled peer. We had a great deal of observational data in inclusive classrooms which included the teaching assistant as part of an interaction. Our data revealed three categories of adult behaviour directly relevant to peer social interactions. Sometimes the adult “facilitated” a social interaction between children—this is the Goldilocks Principle (like the story about the three bears), where what the teacher aide does is *just right*.

Another behaviour we called “blocked” when the adult actually stepped in and interrupted an interaction, taking it over completely. Sometimes these blocks were clearly very negative, while often they could be seen as “coming to the rescue,” to save the day. A little problem occurs, and rather than giving the children space to figure out how to solve it, the adults step in. We cannot wait even a few seconds, we have to show we know what to do. When we come to the rescue, we interfere with developing social relationships as we demonstrate again and again that it is the adult who belongs in this social interaction—not peers or friends.

The third category of adult behaviour comprises missed opportunities—what could be called “teachable social moments” where opportunities for social interactions went unnoticed by adults who might have facilitated the interaction. An example from Adler’s experiences in one of the inclusive classrooms we observed will illustrate this. Adler is 10 years old, is in the 4th year of school in Washington State, and is a very personable, social kid—he loves basketball, videos, pizza, and just being with peers. He is also non-vocal, uses a wheelchair, and has a significant disability. One of the situations we observed was a special lunchtime activity planned for the classroom where the teacher had ordered pizza to be eaten in the room. The observation notes describe the scene with everyone getting ready for this special lunch activity—the students are putting books away, talking, getting up from their seats, and moving the tables to organise the furniture for the pizza lunch. But Adler continues to work, with his teacher aide, Mrs T. seated at his side, guiding him as he copies telephone numbers (an IEP objective). He is very quiet, working away

with direct physical prompting from the adult teacher aide, and not at all involved in what the rest of the class is doing. The classroom teacher has actually left the classroom momentarily, but the children are carrying on quite appropriately having fun getting ready for this lunchtime special activity. A girl in the class moves close to Adler's table and hovers for a few minutes—watching Adler copy telephone numbers. This is a perfect example of a teachable social moment. The teacher aide should have facilitated Adler's participation in what was clearly a social time, stopping the work and focussing instead on the potential for Adler to interact with this obviously interested classmate. Instead, both the teacher aide and Adler show no signs of recognition that she is there, and after a few minutes, the opportunity is lost as the student goes back to the “fun” activity happening in the rest of the room. There is a certain irony in this story—Adler is busily learning to copy phone numbers but, without friends, may have no one to call or who will call him.

Finally, I have a photograph taken on a field trip, with everyone in the class from a school in Brooklyn spending the afternoon in the park. No doubt someone said “This has been such a great day, let's take a picture before we go back to the school,” and here we have it. If you look closely at the middle of the picture you can see the little girl in the front row, Jessica, who is sitting in her wheelchair. What is “wrong” with this picture? Is there anybody who does not really belong in the picture? There, in the front row right next to Jessica is her teacher aide, a really sweet, wonderful woman, highly regarded by all. She is the only adult in this picture of the children. Without any instructions from anyone, the teacher aide just got down there next to Jessica to be forever present in this visual record of a memorable time spent together by a group of children. Jessica did not need “supportive picture taking.” She did not need to have anybody there with her, she was quite capable of smiling for the picture along with everyone else.

Maybe this seems like a little mistake that is not really important, but comments from students about teacher aides reveal another aspect. Here are some of their comments: “Mrs G [the teacher aide] even does Darla's locker for her. Darla can open a lock with a key by herself;” “I used to walk with Darla, but now Mrs G is there packing her bags and she tells me to go ahead;” “Some kids that [sic] would be Darla's friend don't go near her because Mrs G is always there;” and “I don't like being told what to do for Darla all the time; I would do those things anyway because I'm her friend.”

One very sad case study in our data comes from one of our Washington schools, where a little girl and her classmate with severe disabilities were very close friends during the year. They were together in school, invited to each other's homes, and did all sorts of things together all year. As the year progressed (Year 4 in school, they were 8 years old), the teacher noticed this friendship and started asking Beth, the typical child, to help her friend with class work. Beth got asked more and more and more to help and, as time went by, our observational data showed fewer and fewer interactions. At one point, Beth told our interviewer “I don't want to be Mary's teacher's aide.” A year later, the friendship was over. The teacher had taken advantage of a friendship to use Beth to help and, in so doing, had turned a fun relationship into a job for Beth. The relationship was never the same. We cannot

state conclusively that the end of the friendship was a direct outcome of the teacher's well-intentioned actions, but common sense suggests that this played a major role. Note the following comments from young teenagers in one of our focus group interviews:

Sandy: I'm not going to say Valerie can't socialise with us but sometimes she don't, like me and Marisha and Nicole and the other girls sit together but you know she just stays with her para [a common abbreviated term in the region for the paraprofessional]. She doesn't talk to anybody, she just talks to her para.

Kerry: The para is Valerie's friend, they joke around, they talk a lot, they have fun together.

By adolescence, the other teenagers seem almost envious of this relationship between the student with disabilities and the teacher aide. Rather than seeing Valerie as disadvantaged in any way, they told us it must be great having an adult with you to do everything for you and be with you all the time—mentoring you and caring about you. They do not see that there is any space or need for them as peers or friends. This child is well taken care of and that is how they talk about it.

Designing Naturalistic or Do-Able Interventions

A crucial phase of this research is to design naturalistic interventions—what we called “Do-Able” interventions (Meyer & Fisher, 1999). We applied some guidelines to ensure that the interventions would work in real schools and actual family situations as they were at that moment, not as we might like them to be in a perfect world. If typical schools and communities are to carry out interventions, we could not assume additional funding or resources that were not present in those settings. Thus, we did not pursue interventions that were expensive or terribly elegant and sophisticated, things that would not work in the real world. One of our guidelines was that interventions needed to be do-able with available resources. Our research literature is full of examples of elaborate interventions that may indeed have resulted in behaviour change but were carried out with additional staff, additional funding, and in ideal circumstances, with major support from outside researchers. A major problem in putting research into practice is that such interventions are dependent upon those additional resources and cannot be maintained once the special funding or research ends. Thus, in the final phase of our research, we collaborated with teachers and family members to design naturalistic interventions that were totally consistent with the ongoing flow of activities in general education classrooms, families, and community environments. We tried to avoid developing islands in the mainstream and expecting the extraordinary to happen. Researchers must focus on validating interventions that are sustainable over time for schools to make the commitment to maintain strategies that were developed by them in the actual circumstances confronting them day by day. Much of what is written in the

published literature regarding “best practices” may not be possible for many practitioners working in typical schools.

Recently I was asked by a publisher to review a manual submitted for publication consideration. The manual was designed for regular classroom teachers and other team members working in inclusive programs, and the recommended procedures required that the educational team meet one hour per week for each child! Is there anyone out there who has one hour per week to meet on behalf of each individual child in an included classroom? It is not going to happen—and it probably would not even be fair to dedicate this level of resource to programs for students with disabilities in comparison to that received by other children. We cannot keep promulgating these kinds of recommendations or practices—it is just not reality-based to do so.

The team *could* meet for perhaps 10 minutes. However, that team is probably going to comprise two adults at a meeting (the special and general education teachers, for example, or the teacher and teacher aide), not all those people who get listed on the piece of paper filed away on the IEP. Do-Able interventions must also make sense to others—they must be consistent with common knowledge. You should be able to explain the intervention to your grandmother, and if she shakes her head in dismay or confusion you know it will never be done once the researchers leave the scene. Participatory research is absolutely critical for this work. *Practitioners and family members must be involved in the design and implementation of any best practices that we expect will be with us for more than a few weeks and to exist in places other than on the pages of articles published in journals.* The criteria for this concept of Do-Able interventions are described in detail in Meyer, Park, Grenot-Scheyer, Schwartz, and Harry (1998) and examples are given in Meyer and Fisher (1999) and Grenot-Scheyer, Fisher, and Staub (2001).

Summary: Bringing it All Home

To conclude a couple of comments about research. Brew’s (1999) paper is a very interesting discussion on what research ought to be. She says, for example, towards the end of her paper, that academic research has as its primary purpose the generation of socially useful knowledge. Even if it is not always new, it should be socially useful. What if we were to apply the criterium of social usefulness to the research that we do, at least some of it?

During 1998, the President of the New Zealand Psychological Society analysed the most recent research reports published in refereed journals by the Psychology Departments of New Zealand’s seven universities; this information is available in each university’s Annual Report. He sought to determine the extent to which this research was *directly relevant* to New Zealand by using the major criterion that the reported research could not have been done just as easily in the UK or the US. He found that fewer than 40 articles met this criterion (Evans, 1999). Is it not fundamental to the educational research endeavour that we offer important solutions to very real, common social needs? Not all research needs to relate directly to addressing important ongoing problems, here and now. But how much of our

research output *ought* to be directly relevant to real problems? There are serious issues challenging contemporary society and we need to put our heads together to sort out some of those issues and solve some of those problems. Research has to be about socially useful knowledge. We probably need to undergo radical self-critique and soul-searching—a major transformation—if we are going to restore confidence in our ability to solve problems and help overcome obstacles. As higher education institutions, in particular, I am not sure we have a clear view of what it is that we can do or what we should be doing to address some very real social issues.

The front-page story of *The Courier-Mail* (Franklin, 2000) reports that a decision has been made to create five special schools for students with challenging behaviours. (I always hate it when people come from overseas and say something and here I am doing it. I am so ashamed!) In the year 2000, five special schools for children with challenging behaviours from the age of 11 to 15 are reported to be a major new development. This is not exactly a new idea! But all of us will have to accept responsibility for this decision because it looks like we have not been able to communicate in all these years that segregation does not work. What it does is create dysfunctional clusters of however many children we can fit into five schools—alienated and unhappy. How will they learn socially appropriate, positive behaviour when there are no models in that environment except other children with severe challenging behaviour? It cannot work, it will not work. We have had two generations of experimentation in special education proving that it does not work. Why are we not communicating effectively to our policy makers and educational leaders? Why are we not having an impact on practice? Perhaps being a critic and conscience of society or being a researcher does not involve people like me standing up here trying to be smart about something I read on the front page of a newspaper. But we need to be saying: Here is what you can do, please make available that same resource you would have spent on those five schools, and we will all work really hard to make something inclusive work for these children—because they are going to be with us forever. There is no point in sending them away. We have got to figure out how to make it work with these children *with us* on a day-to-day basis.

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