

Invited commentary on the issues of early intervention:

Children and families influenced by the developmental spectrum of conditions known as autism

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Abstract

Research to date indicates that all children benefit from early intervention and children with Autism Spectrum Disorder (ASD) have shown significant increases in development with several types of interventions. Interventions have been shown to have most long term success when they fit with the strengths and capacities of families. Other research indicates that the differences in children within the Autism Spectrum label are often greater than differences to non-labelled children or to children with other labels, so 'one size fits all' is likely to be ineffective. Similarly, normative, inclusive environments have been shown to be beneficial for developing normative behaviour in children with ASD when linked to appropriate interventions. Overall there appears to be little justification for using segregated and congregated environments apart from administrative convenience, and other research indicates that such environments are likely to have significantly poorer outcomes to inclusive models. Similarly, advocating only one or two approaches is going beyond the research evidence at this point. It is argued that as family wishes, skills and capacities are central to favourable long term outcomes for the children, parent choice must be a key element of any program. Interventions must also be relevant to families in rural and remote areas which mean there must be the flexibility to use normative community environments.

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Social deficits are central to the definition of autism¹. From Kanner's (1943)² original conceptualisation to the most recent TASH³ collections⁴, problems in social relatedness have been extensively covered in the literature. In spite of this ubiquitous nature, the adaptive address of these symptoms remains one of the most daunting challenges for the parents and those professionals who serve such children.

There has been an explosion of interest over the past decades as to the timing, type and location of intervention and thus we are pleased to provide the National Council on Intellectual Disability (NCID) with our views on the notion of early intervention, as it applies to children in general as well as to this particular group.

As a starting point, we would like to address several features brought to our attention by Michelle O'Sullivan, parent-teacher and the NCID delegate to the national forum currently addressing this issue. Michelle has outlined for us what she believes are the most salient issues facing our discussions. She asked us to address what we see as the critical features and issues that emerge from the literature surrounding this complex set of conditions towards some sense of a coherent and unified Australian address of the issues. She urges us to appreciate that for families time is fleeting, even increased resources will never be enough, and family's and children's lives too important for this matter to be left to a fractioning of strategies based on something other than evidence-based collaborations. As an overview, it appears to us that research has supported a range of approaches that differ in underlying practice, theory and ideas and yet each of these seem to contain fundamental elements that appear to correspond, not too surprisingly, to those elements found in the normative developmental literature.⁵

We believe it is therefore possible to develop a comprehensive set of collaborative strategies based upon shared assumptions, contemporary Australian values and core findings from the literature. We acknowledge the significant challenge this posits to those who may hold a narrower focus upon a condition or a particularistic treatment method, for it is agreed by most of the field to be a very broad spectrum of conditions and effective treatments.⁶

Our position is that what the broader view creates is a unique opportunity to broaden the focus to early development and what is known about these years, honing in on the range of particular issues as they apply to individual children within this broad spectrum of conditions, with their inimitable skill profiles within unique families and communities.

Importance of families having informed choices

Until relatively recently, large numbers of children with significant impairments did not exist in our society. Before WWII, sadly, most children with severe impairments died before age 10.⁷ From earliest times into the very modern era, institutions proliferated.⁸ Beginning in the 60's and 70's it became apparent that institutional models and the attitudes and values upon which they were constructed were characteristically out of touch with family and cultural aspirations. They were developmentally untenable.⁹ It was found that when residents move out of segregated environments they are more engaged; have greater choice; use more community facilities; increase in their adaptive behaviours; increase contact with

family and friends; are more accepted by the community; have a better material quality of living, and service costs are reduced compared to the institutions.¹⁰

In 1986 the *New Direction* enshrined in legislation our aspiration for development and integration.¹¹ Revisions to the Education Act and policy from 2000 forward, at least in WA, also set the stage for parental involvement as central.¹² Only a brief time ago, the location of education for such children was confined to segregation – some not allowed education at all into the late 1970's. When students completed their education, their most probable life option was also segregated. This segregated tracking system is now being overhauled leaving parents to see the remnants of segregation alongside systems of inclusion. Parents now have access to over four decades of research showing unequivocally that inclusive education produces better outcomes academically and socially for children with an intellectual impairment (including ASD).¹³ It is therefore critical that parents have access to information about this history, the new direction and the research as well as values underpinning each so as to make informed life choices at these earliest and most vulnerable ages.

The importance of families holding senior roles

Social inclusion is but one of those contemporary cornerstone values consistent with the literature. We have moved from Kanner's view of mothers as those to be "treated" to a place where mothers and fathers expect to be included as partners, senior partners, in the care plans of their children.¹⁴ Contemporary and future families will expect to be informed of the breadth of the condition we are addressing and the girth of effective programs. Because of the central role played by parents, historically going back before recorded time, and the evidence that theirs is the most lifelong and ongoing commitment to the child, theirs is and should be the senior role in determining the style of intervention most suited to their unique circumstances.¹⁵

The importance of being responsive to families in rural and remote regions

For many years going back to at least the 70's and 80's, impressive results have been achieved regarding the enhanced development of children and toddlers identified early.¹⁶ Unfortunately the application of the "technology" is not even and widespread. Even today parents are repeatedly put in the position of needing to travel to metropolitan areas, sometimes forgoing their other children's needs, their own needs, their careers and lifestyles, to access early intervention and follow through services.¹⁷

In a country as diverse as Australia, with a need to settle and develop our regions, such a requirement is not only a personal tragedy, but also a national one. Our thinking about model design at this developmental stage must be, "Will this model work regionally, rurally and with isolated families as well as in the city?" It was never tenable to make our rural families the "poor cousins" of their metropolitan counterparts. It was never true that their needs were less than those who live in the city. Technology such as video-link can help bridge these distances and models of rapid and potent deployment of service technologies such as transdisciplinary can be developed, thus we urge that such models be employed as a critical aspect of making as wide if not wider access available to rural and isolated families as those in more populated areas.¹⁸ Dissemination models are therefore challenged to be

creative in always thinking of our unique culture of being a widely dispersed population.

The importance of being responsive to child/family across settings and ages – where interventions and services transcend service sector boundaries

Research on the efficacy of early intervention for a large range of young children with a range of disabilities has demonstrated that family variables are one of the best predictors of early intervention outcome.¹⁹ Families of children with the ASD label are equally diverse in reference to available resources, cultural background, and jurisdictions. (We wish to particularly note rural and remote “diversity”.) It is therefore critical that intervention approaches must consider not only each child's current developmental level, her unique developmental profile of learning strengths and weaknesses but also family locale, circumstances, priorities, and vision before determining the “fit” of the intervention approach within these “variables”.

Children develop in at least 5 domains²⁰, several of which transcend professional and thus structural “boundaries” such as is evidenced in human service designs such as university training and research, government departments of health, education and welfare. Children and families should expect that we are able to rise above these artificially created structures to provide a more seamless interface with families and those community settings which they need to access.

This means that wherever possible, models of service particularly to the youngest of children should, when invited, expect to go into the homes, play-groups and child-care settings where the children and families naturally are, rather than travel at their inconvenience to our centres. That is, if we expect to reach those families most at risk of not participating because of hardship and if we wish to be truly as unobtrusive in people's lives as is possible, we must invest in a structure that brings services to the children in their natural settings – not children to the services.

Early childhood is becoming less the domain of the tradition of “health” and more the domains of child management (child-care) and child-development (day-care, kindy and pre-schools). This trend is fairly new and thus educators can and should play an increased role in the team of people creating bridges across this age and into the increasingly formal schooling years.

Strategies and programs should be developed which honours the toddler and young child years as a time of play with an enhanced awareness of how valuable this play is to development of language, social and cognitive skills and assists a smoother passage into the next phase of the child's life.

Research on inclusive options

Why *early* matters in terms of inclusion

There is a sense of mysticism surrounding the field of early intervention, in particular around those children within this spectrum. It may reflect our cultural unfamiliarity with formal intrusion into the lives of the very young as a generic practice outside of those children who are medically fragile. The image may have been exacerbated by

the uncharacteristic procedures that were contained in some of the earliest forms of interventions²¹.

It is however increasingly known that *early* does matter²² and it matters more than *later*, and it matters for us all in terms of brain development.²³ Brain science, together with the unpicking of the genetic code has made great strides over the past decade. It is increasingly clear that the flexible quality referred to by neuroscientists as “plasticity”, that remarkable ability to learn from and adapt to the various environments we find ourselves in, is laid down in the first 7-10 years of life; much within the first 3 years. The 100 billion or so nerve cells connect together in an extraordinary complexity of what becomes our very unique microcircuitry. We truly become unique through our unique experiences. Plasticity enables us to benefit from experience.²⁴

Learning is a process of building on our current state of knowledge and thus it is elemental that for the child at risk of delayed or slowed development, the foundations of each skill are as carefully layered as we can design. The “function” of such design cannot be determined without reference to the context and future life of the child, their family and community²⁵ and thus our focus on contemporary Australian values as one of the guides we must consider.

Why Social Inclusion

Social inclusion is one of these contemporary cornerstone values. Culminating in the passing of the landmark legislation known as the *New Direction*, Australia has shifted its course from segregation as a cornerstone in the treatment of difference towards integration and, in its more advanced form, inclusion.²⁶

Although we continue to label children with developmental delays, according each label with unique patterns and characteristics, most children with the condition known as autism spectrum share many behavioural patterns with other children, including those without and with other disability labels. There are in fact few efficacious, label-specific educational practices reported in the literature and this extends to autism (i.e., educational practices that are effective with all children who have autism and only with children who have autism).²⁷ Moreover we can find little if any justification for the widespread practice of segregating and congregating children around a label in order to provide an intervention, with all interventions able to be carried out within normative environments with a small amount of creativity. This is surprising given the extensive research on the benefits of inclusion in mainstream education mentioned above and the obvious disadvantages of grouping around a label coming from poor models and low self esteem associated with label-based grouping.

Thus, much of what we have learned from factors that influence other children’s development is also applicable to children with autism. This is not to diminish in any way from the great advances in the work of those whose focus is purely upon this condition. Rather, our position is that it extends outward from this to connect with what children – both those with and without disability labels - share in common. This strength-based approach focuses us on capitalising on all that we know in the developmental realm.²⁸

Why social & curricular inclusion from a science point of view

Programs from a social and curricular inclusion point of view suggest an organisational attempt to increase the likelihood that children will develop skills and have the interactions that promote learning of adaptive and positive behaviours.

We are beginning to realise from the emerging brain research that all interactions and observations children have will influence their development - including those interactions we plan and those that occur outside of our formal interventions.

Formal hours of intervention, even with highly boosted intensity, are small in comparison to non-formal intervention time. (i.e., a child is awake and thus learning for over 10,000 hours before three years of age.) Compared with even the most intensive 40 hour a week program of 1600 annual hours, the child is awake for some 5000 hours annually from age 3. Much of this time is typically spent with families.²⁹

Each moment of interaction and observation may promote learning, block learning, promote maladaptive learning or have little influence³⁰; therefore it is critical that we extend interactions into naturalistic environments such that the important moments are captured. We need to include those that are based on the child's attention, those that are self-directed and those that are directed or responsive to adaptive development as well as minimise maladaptive learning and practice.

Such interactions are likely to result in more learning than those that do not capture the children's attention in informal as well as formal instructional connections. Inclusive strategies must extend the number and quality of good observers and interpreters of children's behaviours so as to respond in flexible and contingent ways to capitalise upon plasticity. We also know that children must learn to generalise skills, no matter how intensive the program, to locations where they are required (i.e., homes and schools). Fortunately practices recognised in the literature and in current practice document the efficacy of working within typical environments, using natural contingencies and building self-control techniques.³¹ On the other hand, working within non-normative segregated environments throw up the challenge of generalising the behaviour learnt to the natural environment.

Although children with the conditions known as autism share similar developmental challenges in the general areas (e.g. social-emotional reciprocity, communication reciprocity, cognition and sensory development), remarkable heterogeneity exists within this population. It is therefore essential to development of an adaptive societal response to be cognizant that a child within this broad label may have *more* in common with another child with or without a disablement label (e.g. behaviour problem/language delay) than with another child on the same spectrum with the same label.³² This extent of heterogeneity alone suggests strategies that apply to function rather than mere label should be strongly considered.

Although some older review literature suggests little evidence for inclusion (e.g. Mesibov & Shea, 1996³³) the literature is now rich in exemplars of inclusive models that suggest that other things being equal, the superiority of inclusive models over those that segregate. As far back as 1993, Strain and Cordisco report; "the largest ongoing longitudinal study conducted to that date on inclusive, early intervention for children with autism ... demonstrates long term outcomes that have not been surpassed by any segregated service delivery model."³⁴ Their findings and

conclusions were again validated in 2006 where they report their review has maintained its integrity over the intervening time period.³⁵

Supplementing this longitudinal study is a host of others showing that:

- Many successful programs include typically developing peers (Dawson & Osterling, 1997 – in Roberts and Prior, 2006³⁶).
- Typical age-peers can be taught easily to facilitate social and communicative abilities of classmates with autism. (Goldstein & Kaczmarek, 1993; Kohler, Strain, Shearer, 1992; Odom & Strain, 1986; Strain & Fox, 1982; Strain, Hoyson & Jamieson, 1985; Strain & Odom; in Strain & Cordisco, 2006.³⁷)
- Comprehensive outcomes on standardized assessments, communication skills, social interaction skills, and play skills of children with autism in an inclusive setting (Stahmer & Ingersoll, 2004, in Bruinsma, Koegel & Koegel 2004³⁸)
- Children with autism can be taught to initiate interaction with adults and peers (Koegel et.al., 2001³⁹; Koegel et.al., 1999⁴⁰)
- Peers can contribute considerably to the development of social and communicative competencies. (Koegel, 2001; Hartup, 1983; McGee, Feldman & Morrier, 1997; Strain, Guralnick & Walker, 1986; Odem, McConnell & McEvoy, 1992; in Koegel, 2001.⁴¹)
- Simply being in physical proximity to typical peers reduces the level of “autistic-like” behaviours observed in some young children with autism. (McGee et.al., 1999; Hecimovic, Fox, Shores & Strain, 1985; McGee, Paradis & Feldman, 1993 in Strain & Cordisco, 2006.⁴²)
- Greater opportunities to build friendships and have normative role models for socialisation. (Koegel, 2001; Kohler & Strain, 1999; Nickels, 1996; Peck & Cooke, 1983 in Koegel, 2001.⁴³)
- Segregated settings can have a maladaptive effect on generalisation and maintenance of skills. (Strain, 1983 in Strain & Cordisco, 2006⁴⁴)
- Although *behavioural readiness* strongly influences segregated program design, there is no data to support this claim. (Strain & colleagues, 2001 in Stahmer & Ingersoll, 2004)
- Social development requires early inclusion. (McGee, Almeida, Sulzer-Azaroff, & Feldman, 1992.⁴⁵)
- Children with autism do learn to speak with highly structure discrete trial, however research shows that children are better able to transfer their language to new settings and people following planned, incidental teaching. (McGee, Krantz, & McClannahan, 1985 & 1986 in McGee et.al. 1999.⁴⁶)

- Children with severe disabilities in inclusive settings made greater language and social skill gains than did similar peers in segregated settings (Rafferty, Piscitelli, & Boettcher, 2003; in Snell et al 2003⁴⁷)
- Social interactions can be taught and learned; social interaction in typical settings can be successfully accomplished, and substantial positive outcomes accrue. (Kennedy and Shukla, 1995; in McConnell, 2002⁴⁸.)
- Research studies provide a rich source of intervention options. Intervention strategies have been documented as successful in the process of including students with autism in general education classrooms - antecedent procedures, delayed contingencies, self-management strategies, peer-mediated interventions, and multicomponent strategies. (McConnell, 2002⁴⁹)

And also the current limitations of research qualify that:

- A wide range of approaches that differ in philosophy, ideas, strategies and locations have shown effect⁵⁰.
- *No one approach is equally effective for all children.* Not all children in outcome studies have benefited to the same degree from a specific approach.^{51 52}
- Most studies have focused only on child variables and child outcomes and not parent variables.⁵³
- "Intensity of treatment" is neither well defined nor differentiated from the normatively known impact of 'engaged time'.⁵⁴
- The fidelity of treatment methods are rarely "measured" or discussed⁵⁵.
- Variables outside of the 'the object of study' are rarely examined.⁵⁶
- Some research, such as on the effect of early literacy, shows promise but is insufficiently documented at this point⁵⁷

The weight of these studies taken together with these research foibles, leads us to conclude that autism specific separations for program design would be less efficacious than a broader, more inclusive design where intervention can be specifically tailored to the uniqueness of the presenting conditions.⁵⁸ This would also lead to the maximisation of family choice and relevance to rural and remote environments. Although the benefits from inclusive early interventions are significant, inclusive early interventions are rare. Given these factors, one should also consider the moral direction of the society – which, since at least 1986, has been seeking to include diversity.⁵⁹ It is also noted that social inclusion is a key objective of the new federal Labor government.

How to distribute funding equitably and efficaciously

Is it possible to discern who is most likely to benefit from intervention?

We are not convinced that “most likely to benefit” is discerned nor is it discernable within the literature. This is not because there is not good science. It is merely because of the nondeterministic, probabilistic nature of development.⁶⁰ Even the strongest proponents of their treatment admit that it is not effective with every labelled child and most go further in not being able to discern this at the point of referral.⁶¹ This is no surprise, given the unpredictability of child development in general. Although early experiences are important for later outcome, this does not imply that the effects of any one type of early experience are necessarily causal. Each individual has a unique combination of factors influencing outcome and therefore it may be wiser to determine which factors are most likely influenced and distribute resources accordingly.

As with most such “equity decisions”, these are more moral and socially value based than they are empirical ones. That is, it certainly can be said, that moving the most impaired child to a greater degree of independence – even if only in small ways - will, over the lifetime of a child, produce “bang for the buck”.

Equally it can be said that for the child who is mildly impaired, given significant intervention we can produce at least short-term “recovery” results. (This can also be said with children with other conditions.) It can NOT however, be said that one benefits “more” and one “less” but only that their starting points and developmental trajectories differ, as do their conditions, their genetics, their locale, environment and so on.

It is therefore incorrect to say that one “benefits” and another does not and therefore one “deserves” resource dollars and another does not. To say this would be a return to the pre-60’s when we falsely believed some children were “ineducable” and therefore “undeserving of educational experiences.” We were wrong then and we would be even more wrong to take this position given the extensiveness of experience during these past 50 years.

What would be an equitable basis for resource distribution?

A “social judgement” is called for. It is our view that equity seeking “bang for the buck” is a matter of something other than within the child’s profile of delay alone. We propose these variables be considered as more coherent determiners of “fairness” in resource distribution.

For the child and family:

1. Parents seeking help with a child who is delayed in development.
2. Willingness to participate in an evidence rich intervention.

For the provider

3. Willingness to participate in an evidence rich intervention with longitudinal follow up.

4. Willingness & ability to provide intervention that has fidelity with family and procedural approach (followed faithfully, reliably and “fits” with family variables and values noted earlier.)
5. At this point, one may determine that the child with the greatest and multiple delays is deserving of the greatest investment. This would be a sound moral judgement with which we agree.
6. It may also be a next measure of fairness to consider that those children most remote from an array of choices and an array of informal supports should also receive some priority. It would be the measure of the morality of our society to give positive discrimination in these last 2 ways.

Having covered, at least briefly, the matters put before us, we now turn to some residual issues for considerations. These are by no means complete (given our restricted timeline) however they are provided for the sake of the Council’s deliberations:

What other factors are suggestive of making a difference?

1. The long term factors of poverty, health, violence, nutrition and stress of expectant mothers cannot be overlooked as even earlier, related early interventions that must be considered from a holistic view. Albeit possibly beyond the scope of this funding project, collaboration across the health, welfare and educational domains in an effort to train all to respond adaptively to these factors is a critical piece towards making a difference.
2. Earliest identification is suggestive of the need for greater public awareness and the need to train providers in all areas of very young children’s lives to identify developmental delays at their earliest onset and facilitate access to evidence rich, developmental interventions. Osterling and Dawson⁶² suggest we can and should detect autism in most cases in infancy and yet it is not typically diagnosed until around 3-4 years⁶³. We can discern “what works” but our abilities to be predictive before intervention on an individual basis are notoriously poor.
3. This is not a condition where “cause” and presentation of certain behaviours are homogeneous across the population of “diagnosed” children. This breadth of heterogeneity gives rise to the need to examine numerous aspects of any proposed programs to address the issues with some level of social and technical coherency.

Given the current overburdening of doctors with the medicalisation of developmental problems⁶⁴, such as Rowe uncovered in the reading review, we should seek to focus the specialists, especially expensive specialists, upon those aspects which match with their professional expertise. This money could be, for instance, “quarantined” to:

1. The aforementioned long term factors of poverty, health, violence, nutrition and stress of expectant mothers.
2. Development of neurobiological frameworks for study of interventions and translation of that knowledge into meaningful actions.

With what presents as a unique set of functional developmental delays, using exclusively a medical basis of diagnosis may not be the most frugal long-term strategy. Further, it may perpetuate a medical model of referral and definition which is not particularly well matched with current treatment effect modalities that lie

primarily in the developmental, educational and socio-behavioural realms. In other words, the current treatments are not medical treatments-in the main. They are psycho-social-educational and therefore needed to be assessed and treated as such.

Conclusion

Intervention approaches should be individualised to match a child's current developmental level and profile of learning strengths and weaknesses. We agree with Shaddock, King and Giocelli that "disability" and particularly this sub-category is not a uni-dimensional construct and it is incorrect and potentially misleading to generalise about 'students with disabilities' as it is 'children within this spectrum'.⁶⁵

As posited throughout the literature, remarkable heterogeneity exists within this population. Families of children with the conditions are equally diverse in reference to available resources, cultural background, and so forth.⁶⁶ Thus, our intervention approaches must consider each child's current developmental level as well as profile of learning strengths and weaknesses, family priorities, and the "fit" of the intervention approach within the "culture" and lifestyle of a family. Each child as well as each family varies greatly in the supports needed to achieve these goals.⁶⁷

It is our contention that approaches that are limited in practice to one or two modalities of intervention (e.g., discreet trial or primarily speech training) are at risk of missing significant developmental needs of the children for social behaviour, communication systems as an augment and so on. Therefore the importance of developing an individualised and whole of child approach cannot be overstated.

We agree with Shaddock, King and Giocelli that the pedagogical focus must shift from 'adaptations for special needs or disability' to 'universal design pedagogy'.⁶⁸ Rowe emphasised this point in the NITL and it has been increasingly becoming clear that there is no such paradigm as special needs.⁶⁹ Rather, intensively applied, typical pedagogy is the core of "what works".⁷⁰

Finally, we believe there is a need to listen very carefully to families. The movements to inclusion and family-centred practice in early intervention have been based largely on family-systems theory, moral and social values and theories underpinning these. Parent advocacy organisations, not researchers, played the major role in advocating for legislation for such practice in the 1970's & 80s. The educational and clinical efficacy of inclusion and family centred practice has been demonstrated only *after* such practice has become required. A clear history exists of practices changing on the basis of social values. The use of aversive strategies such as punishment and electric shock to reduce "self-stimulatory" behaviours and requiring eye' contact training as a prerequisite to other skills were once "commonly accepted" as were segregations of children in small and large groups for the sake of experimental and administrative convenience. These and other such practices are no longer advocated by most- yet such procedures were in effect at the time of major outcome studies upon which we base much of our current thinking. It is time to move to a new paradigm based on contemporary values of social inclusion, families as the core of decision making for children and evidence based approaches that are holistic and communal in nature, rather than on technologies that have their roots in an institutional culture.

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- See also Strain (2006) cited in endnote 27. Strain submits that our first assumption must be that *children with autism are children* and that *much of what we have learned from other children may be applicable to children with autism*.

²⁹ Koegel, L.K., Koegel, R. L. Harrower, J.K. & Carter, C.M. (1999). *Research & Practice for Persons with Severe Disabilities*, 24, 3, 174-185

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³² See Roberts, J. M. A., & Prior, M. (2006). A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. *Australian Government Department of Health and Ageing, Australia. It is important to account for the spectrum of autism disorders and to recognise that while the core characteristics of autism spectrum disorders are consistent, no one child with autism will have the same pattern of strengths and needs as another. In addition families differ in their goals and resources, strengths and needs*.

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³³ Mesibov, G. B. & Shea, V. (1996). Full Inclusion and Students with Autism. *Journal of Autism and Developmental Disorders*, 26, 3, 337-346

³⁴ Strain, P.S. & Cordisco, L.K. (1993). LEAP Preschool. In S.L. Harris & J.S. Handleman (Eds.) *Preschool Education Programs for Children with Autism*. 225-252. Austin TX: Pro-Ed.

³⁵ Strain, P.S., Wolery, M., & Izeman, S. (2006). Considerations for Administrators in the Design of Service Options for Young Children with Autism and Their Families. Republished by the Autism Association of Colorado with new introduction by the authors. Originally published in young *Exceptional Children*, 1, 2, 1998.

³⁶ Roberts, J. M. A., & Prior, M. (2006). A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. *Australian Government Department of Health and Ageing*, Australia.

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³⁸ "over time and with intervention, these children benefit from typical peer proximity, especially if they are taught to initiate towards them."

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⁴³ Koegel, L.K., Koegel, R.L., Frea, W.D. & Fredeen, R.M. (2001). Identifying Early Intervention Targets for Children with Autism in Inclusive School Settings. *Behaviour Modification*, 25, 5, 745-761

⁴⁴ Strain, P.S., Wolery, M., & Izeman, S. (2006). Considerations for Administrators in the Design of Service Options for Young Children with Autism and Their Families. Republished by the Autism Association of Colorado with new introduction by the authors. Originally published in *Young Exceptional Children*, 1, 2, 1998.

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- Snell, M. E., Chen, L., & Hoover, K. (2003). Teaching Augmentative and Alternative Communication to Students With Severe Disabilities: A Review of Intervention Research 1997-2003. *Research & Practice for Persons with Severe Disabilities*, 31, 3, 203-214
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- McConnell, S.R. (2002). Interventions to Facilitate Social Interaction for Young Children with Autism: Review of Available Research and Recommendations for Educational Intervention and Future Research. *Journal of Autism and Developmental Disorders*, 32, 5, 351-372.
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- ⁵⁰ - See Dawson, G & Osterling, J. (1997). Early Intervention in autism: Effectiveness and common elements of current approaches. In M. Guralnick (Ed.). *The effectiveness of early intervention: Second generation research*. (pp. 307-326). Baltimore: Paul H. Brookes; & Rogers, S.J. (1996). Brief report: Early intervention in autism. *Journal of Autism and Developmental Disorders*. 26. 243-246 for reviews. Long-term outcome studies (e.g., Greenspan, S. & Wieder, S. (1997b). Developmental patterns and outcomes in infants and children with disorders in relating and communicating: A chart review of 200 cases of children with autistic spectrum diagnoses. *Journal of Developmental and Learning Disorders*, 1, 87-141; & McEachin J.J., Smith, T. & Lovaas, O. I. Long-Term Outcome for Children With Autism Who Received Early Intensive Behavioral Treatment. (1993). *American Journal on Mental Retardation*, 97, 4, 359-372.) and shorter term treatment efficacy research (Ozonoff, Sally & Cathcart. (1998). Effectiveness of a home program intervention for young children with autism. *Journal of Autism and Developmental Disorders*, 28, 25-32.; Rogers, S.J. and H. Lewis (1989). An effective day treatment model for young children with pervasive developmental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry* 28, 207-214; Sheinkopf, S.J. & Siegel, B. (1998). Home-based behavioral treatment of young children with autism. *Journal of Autism and Developmental Disorders*, 23, 15-23.) demonstrate effectiveness of approaches that vary in philosophy and practice.
- ⁵¹ No studies that we have seen directly compare the effectiveness of two or more approaches by use of randomly assigned, matched-pair control samples. These are
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difficult to arrange. They are rare. Yet they would be required to make direct comparisons.

- See Roberts, J. M. A., & Prior, M. (2006). A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. *Australian Government Department of Health and Ageing, Australia.*

A consistent finding in research studies is that different children with autism respond in different ways to any given treatment or intervention program. Therefore, it is important to note that there is no single program that will suit all children with autism and their families. There is however evidence to suggest that there are substantial short and long term benefits from early, intensive, family-based treatment programs, whatever their theoretical basis, so long as these are appropriately adapted to the child's pattern of strengths and weaknesses and take account of family circumstances.

- See also McConnell 2002, cited above, *As yet, there are no published large-scale "technique testing" investigations that explore the relative effects of different social interaction interventions specifically for children with autism.*

⁵² - Dawson, G & Osterling, J. (1997). Early Intervention in autism: Effectiveness and common elements of current approaches. In M. Guralnick (Ed.). *The effectiveness of early intervention: Second generation research.* (pp. 307-326). Baltimore: Paul H. Brookes.; Rogers, 1996.

- The two studies receiving the greatest attention in recent years (i.e., Greenspan, S. & Wieder, S. (1997b). Developmental patterns and outcomes in infants and children with disorders in relating and communicating: A chart review of 200 cases of children with autistic spectrum diagnoses. *Journal of Developmental and Learning Disorders*, 1, 87-141; & McEachin J.J., Smith, T. & Lovaas, O. I. Long-Term Outcome for Children With Autism Who Received Early Intensive Behavioral Treatment. *American Journal on Mental Retardation*, 97, 4, 359-372.) have reported the most positive outcomes in 58% and 47% of the children, respectively.

⁵³ Family variables, which are considered to be critical variables in early intervention outcome research, have rarely been addressed in a comprehensive manner in research on children with this spectrum of conditions (Gresham, F.M., & MacMillan, D.L. (1997). Social competence and affective characteristics of students with mild disabilities. *Review of Educational Research*, 67, 377-415. Prizant, B. M. & Wetherby, A. M. (1998). Understanding the continuum of discrete-trial traditional behavioral to social-pragmatic developmental approaches in communication enhancement for young children with autism/PDD. *Seminars in Speech and Language*, 19, 329-353.). Such variables include family structure (i.e., number of parents/relatives directly involved in care-giving, number, ages, and birth order of siblings), socioeconomic status, parent education and occupation, formal and informal supports (e.g., parent participation in support groups, extended family supports, involvement in a religious community), and additional stressors on the family, Seminal research on efficacy of early intervention for a large sample of young children with a range of disabilities (Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., & Upshur, C. C. (1992). Development of infants with disabilities and their families: Implications for theory and service delivery. *Monographs of the Society for Research in Child Development*, 57 (6, Serial No. 230).) has demonstrated that family variables are the best predictors of early intervention outcome. Nevertheless, the impact of family variables has not been considered in research on children with ASD

(Greenspan, S. & Wieder, S. (1997a). An integrated developmental approach to interventions for young children with severe difficulties in relating and communicating. *Zero to Three*, 17, 5-17. ; McEachin J.J., Smith, T. & Lovaas, O. I. Long-Term Outcome for Children With Autism Who Received Early Intensive Behavioral Treatment. (1993). *American Journal on Mental Retardation*, 97, 4, 359-372.).

⁵⁴ Factors associated with better outcomes are earlier and more "intensive" interventions (Green, G. (1996b). Early behavioral intervention for autism: What does research tell us? In C. Maurice, G. Green, & S. C. Luce (Eds.), *Behavioral intervention for young children with autism: A manual for parents and professionals* (pp. 29-44). Austin, TX: PRO-ED.; Greenspan, S. & Wieder, S. (1997a). An integrated developmental approach to interventions for young children with severe difficulties in relating and communicating. *Zero to Three*, 17, 5-17.), however little discussion has taken place on how intensity is to be defined, whether a "critical period" exists for onset of intervention, whether *time in terms of hours per week is crucial*, (generic) or differentiated from what is a well known variable of ALL child development (e.g. engaged time). It may very well be that other "secondary" variables such as family structure, resources, and supports are more critical. (Secondary because they would allow some families to engage in more demanding and "intensive" interventions and for others it would be prohibitive.

⁵⁵ When comparing approaches, it is important to examine how well procedures are followed by those who are given the day to day charge of delivery. It is our experience that attributing a particular label to an approach (e.g., ABA versus developmental) may be more reflective of the influence that a program administrator or researcher has than what goes on in actual practice with children.

⁵⁶ Much of the research is unable to control or report on the quality and nature of learning experiences outside of the defined "treatment". For example, families who attribute their child's progress to a particular therapy will also have their child in regularly scheduled activities such as play-group, receive services from speech – therapy, engage with child-care and so forth. Multiple interventions and activities are more reflective of the current scene where parents are seeking all of the help they can get. This should be expected and thus it is difficult to determine whether change is due to a specific intervention, to other life events, or to a combination of these influences. This problem remains a major shortcoming of most outcome research.

⁵⁷ Teo, T & Jackson, R. Understanding children with autism. Paper presented at the national day care conference, Melbourne, Victoria. 15-19 June 2000.
<http://www.include.com.au/papers/autism.pdf>

⁵⁸ Jackson, R., Chalmers, R. Wills, D. (2004) *Should Schools Include Children with Disability?* *Interaction* 17/2.

⁵⁹ 1986: Disability Services Act, 1991: UN Salamanca Statement, 1992: The Disability Discrimination Act, 1996: In WA - Education Department joined with the Disability Service Commission to form the Pilot Inclusive Education Program, 2002 WA Education Review outlines 7 principles of a new education system, 1 being:- Inclusive schools being a central concept.

⁶⁰ Dawson, G., Ashman, S. B. & Carver, L.J. (2000). The role of early experience in shaping behavioral and brain development and its implications for social policy *Development and Psychopathology*, 12, 695 – 712

⁶¹ Horner, R. Meyer, L & Fredericks, H.D. (1986). *Education of Learners with Severe Handicaps: Exemplary Service Strategies*. Paul H Brookes.

⁶² Dawson, G & Osterling, J. (1997). Early Intervention in autism: Effectiveness and common elements of current approaches. In M. Guralnick (Ed.). *The effectiveness of early intervention: Second generation research*. (pp. 307-326). Baltimore: Paul H. Brookes.

⁶³ Dawson G., Ashman S.B., & Carver L. J. (2000). The role of early experience in shaping behavioral and brain development and its implications for social policy. *Development and Psychopathology* 12, 695-712

⁶⁴ Commonwealth of Australia. (2005). *Teaching Reading*. The National Inquiry into the Teaching of Literacy. Department of Education, Science and Training.

⁶⁵ Shaddock, A. Smyth King, B. & Giorcelli, L. (2007). A Project to Improve the Learning Outcomes of Students with Disabilities in the Early, Middle and Post Compulsory Years of Schooling *Australian Government Department of Education, Science & Training, Research*. Project 03176

⁶⁶ See Roberts, J. M. A., & Prior, M. (2006). A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. *Australian Government Department of Health and Ageing, Australia. It is important to account for the spectrum of autism disorders and to recognise that while the core characteristics of autism spectrum disorders are consistent, no one child with autism will have the same pattern of strengths and needs as another. In addition families differ in their goals and resources, strengths and needs.*

⁶⁷ Prizant, B. & Rubin, E. Tenets of Best Practice in Contemporary Issues in Interventions for Autism Spectrum Disorders. *Research & Practice for Persons with Severe Disabilities*, 24, 3, 199-208

⁶⁸ Shaddock, A. Smyth King, B. & Giorcelli, L. (2007). A Project to Improve the Learning Outcomes of Students with Disabilities in the Early, Middle and Post Compulsory Years of Schooling *Australian Government Department of Education, Science & Training, Research*. Project 03176

⁶⁹ Wills, D. & Cain, P. (2003). A World Without 'Special Needs' – The "Naked" Truth. *Interaction*, 16, 4, 32-34

⁷⁰ Commonwealth of Australia. (2005). *Teaching Reading*. Report and Recommendations. *National Inquiry into the Teaching of Literacy, December 2005*.

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