



SUBMISSION

by

A.E.I.O.U. Inc

("AUTISM EARLY INTERVENTION OUTCOMES UNITS")

to

THE HOUSE OF REPRESENTATIVES

STANDING COMMITTEE ON FAMILY AND HUMAN SERVICES

on

BALANCING OF WORK AND FAMILY

Contact: Dr James Morton (Chairman)

Summary: Balancing Work and Family with a Child with Autism

The Australian Government can assist families with a young child with autism to balance their work and family responsibilities by facilitating access to high quality early intervention programs.

This can be achieved by:

Providing equitable support to a child with autism attending a full time early intervention program as that child would receive attending a mainstream childcare centre. This includes but is not limited to:

1. Providing parents Childcare Benefits and Childcare Rebates on fees charged.
2. Providing full time early intervention programs with access to Inclusion Support.
3. Removing the cap on the number of placements within any one centre that can receive Inclusion Support.
4. Increase the total funding allocated to the Inclusion Support Scheme.

The benefits linked to this proposal include:

The provision of a broadly available, affordable early intervention program for young children with autism would provide substantial benefits to these children, their families, government and the general community.

By providing these children with skills to deal with their condition at a young age we are optimising their chances of proceeding to mainstream education and setting them on the path to eventual independence, employment and enhanced quality of life.

By providing families with access to such programs we will see direct benefits in family relationships, work opportunities and family cohesion.

From a government perspective extension of existing funding (provided to mainstream childcare providers) to specialist early intervention services means greatly enhanced outcomes from an existing funding initiative.

Finally, the long term cost savings to the community are enormous, with estimates suggesting that each placement in early intervention can save, over the lifetime of the child, \$1.2M - \$2.0M. This would equate to total annual savings of \$1B (based on 800 new diagnoses each year), at an annual cost to government of \$30M (based on 2 years of early intervention with Inclusion Support of \$19,000 pa per child).

1. Autism Spectrum Disorder:

Autism is a developmental disorder characterised by impairments in communication and social activity. The World Health Organisation definition (National Institute of Mental Health 2004) includes impairment of communication (failure to develop normal communication), social relatedness (abnormal social relationships and social developments), and imagination (interests and activities that are restricted and repetitive rather than flexible and imaginative).

There is a well recognised association with autism and learning disability: the rate of autism in children with a severe learning disability is at least 30% and up to 75% of individuals with autism have a severe learning impairment (O'Brien and Pearson 2004). Long term studies of adults with autism highlight the costs of lifelong support (50-60% live with parents, more than 30% in residential care, more than 50% requiring help with managing money and paying bills, 40% requiring help preparing a meal, and only 10% in employment).

The impact of an autistic child on the family is profound with reduced marital happiness, family adaptability and family cohesion (Higgins, Bailey and Pearce 2005). Seitzer (2004) notes high levels of stress, mental health symptoms and depression, and increased marital discord compared with parents of a child with Down's syndrome, cystic fibrosis and typically developing children. Warfield (2005) reported that Mothers of children with special needs found obtaining and maintaining employment problematic, while noting that employment was also a source of respite. Loynes (2001) reported that the responsibilities of caring impacted significantly on a parents ability to work. Ongoing dependency, financial difficulties and limits on family activity imposes on siblings and other family members (Higgins, Bailey and Pearce, 2005).

Recent Australian research suggests 1:300 Australian children will be diagnosed with autism between the ages of 2-5 years (Williams 2005). Studies soon to be published confirm an incidence of 1:150 which matches European and US data (Dr John Wray, personal communication). This equates to 50000 Australian children diagnosed with autism, with a further 7 Australian children being diagnosed each working day. The cause of autism is unknown but genetic factors are integral, with the incidence being 10% in male siblings and 80% in identical twins.

The average lifetime cost for a person with autism has been estimated at £2.94M (Jarbink and Knapp 2001) which does not include the costs to other family members associated with lost vocational opportunities and other complications listed above (Jarbink and Knapp 2003). Extrapolated to the Australian community this suggests that the cost of autism exceeds \$8B annually!

2. Early Intervention in Autism

Early intervention refers to a broad array of activities designed to enhance a young child's development. Increasing evidence supports the benefits of targeted efforts to enhance learning opportunities and development in the early years, with dramatic shifts in competency observed in children with a variety of impairments, including children with autism when they are participant in intensive, systematic early intervention programs (Ramey and Ramey 1998).

Dunlop and Fox (2000) propose 4 tenets supporting the efficacy of early intervention in children with autism:

1. Impairment in communication skills is a key characteristic of autism. These skills develop significantly during the early years.
2. It is easier to functionally analyse the meaning of a child's behaviour at this age, and hence develop individual programs that better meet the specific needs of the child.
3. Greater collaborative success between families and their children have been observed at this younger age.
4. Autistic behaviours can place the child, family and peers at risk and need to be addressed early.

Ramey and Ramey (1998) have identified key principles for successful early intervention:

1. Principle of developmental timing: Intervention that commences earlier and lasts longer tends to be more successful.
2. Principle of program intensity: more intensive programs have more success than less intensive ones.
3. Principle of direct (versus intermediary) provision of learning experiences: Interventions that provide more direct educational experiences deliver more significant and longer lasting benefits compared to intermediary routes (such as parent training).
4. Principle of program breadth and flexibility: Broader, more comprehensive programs providing multiple routes to enhancing development are generally more effective than narrower ones.

Studies of successful strategies repeatedly demonstrate the importance of early entry, program intensity (minimum of 20 hours per week) and duration (minimum of 2 years), effective transition to mainstream settings, and baseline function on outcome, with broad improvements noted in most children and "normalisation" in up to 50%.

3. Currently Available Early Intervention Services. For Children with Autism

Options for parents in Australia include home based programs (cost \$40,000 - \$60,000pa: directed by a specialists with the intervention applied by teams of students and family members), Special Education Units (State Education Departments, 1 hour play groups until 3-4 yrs, then part time programs 8-12 hours per week, not autism specific, government funded), and State Autism Association programs (part time 8-12 hours per week, 1 year only).

AEIOU provides Queensland's only full time early intervention program for pre-school children with autism. The AEIOU pods will be open for 40 hours per week (matching long stay childcare) and licensed as childcare centres. The intensive AEIOU program operates for 25 hours per week, with a staff: child ratio of 1:2. Programming is provided by 3 specialists and 3 teacher aids. An additional specialist will be employed to provide transitional guidance (from AEIOU to school) and maintain an ongoing relationship with children and their families after they have completed the program.

The cost of the program is \$32,000 pa per placement with an additional cost of \$5,000 pa per placement for the transition/support component (total program cost \$37,000 pa per placement).

4. Childcare, Children with Autism and Early Intervention

Family and Community Services (FaCS) provides income assessed CCB funding and Childcare Rebates for children attending childcare centres. In addition, the Inclusion Support Scheme (ISS) provides up to \$19000 per child per annum for high needs children to attend childcare centres. A cap on the number of placements (10% of the total centre population) that can receive such funding is in place. This funding is used to employ a childcare worker, whose role is to reduce the general workload associated with the high needs child. There is no requirement for the childcare worker to have any training in the care of children with autism, much less to have expertise in early intervention strategies.

FaCS has advised AEIOU that:

1. That Early Intervention is a State Government responsibility.
2. AEIOU children should be eligible for Childcare Rebates and CCB funding.
3. AEIOU should be eligible for ISS for the time that the child spends in a mainstream centre. Where an AEIOU pod is linked to a Childcare Centre fractional ISS funding would be available for the period of time the child spends within the mainstream structure, but there will be no funding for the time the child spends in the adjacent building participating in the AEIOU program.
4. There is a degree of flexibility in the placement caps suitable for ISS support.

This response is associated with a number of inequities and missed opportunities:

1. **Equity of Access:** A child with autism does not develop normal social skills and is unable to cope within a mainstream environment. The above funding strategy does not provide equity of childcare access for these children.
2. **Equity of Funding:** A childcare centre is provided with up to \$19 000 to support children with autism, whilst AEIOU, which is providing all the services of a childcare centre (not to mention a high quality early intervention program) is excluded from this funding stream.
3. **Missed opportunity:** The preschool years are the period of greatest learning, and are critical to providing a child with autism with the skills to participate in the mainstream world, giving them the best chance to proceed to mainstream education and eventual independence. A child with autism in a childcare centre is missing out on this key opportunity to overcome their disability.
4. **Poor investment:** The Federal Government currently provides ISS to mainstream childcare centres. There are no educational outcomes linked to such funding. Realignment of existing funding to specialist providers such as AEIOU can provide a substantial educational opportunity to these children, enhance the vocational and home environs for their families, result in superior educational outcomes from existing government investment, and produce long term cost savings to government.
5. **Opportunity to leverage State Government responsibility:** The major argument provided by FaCS for not supporting this proposal is that early intervention for children with autism is a State Government responsibility. Unfortunately this investment is not being made, and in many states (excepting Queensland) funding in this area has been progressively eroded. As outlined in (4) the Federal Government has the mechanism and resources to make a major contribution to Early Intervention for children with autism through the ISS.

Linkage of such support to matched State Government investment would ensure that programs are adequately resourced.

6. Opportunity to develop a childcare linked preschool curriculum for the largest group of special needs children with a learning disability.

5. Conclusion

The provision of a broadly available, affordable early intervention program for young children with autism would provide substantial benefits to these children, their families, government and the general community.

By providing these children with skills to deal with their condition at a young age we are optimising their chances of proceeding to mainstream education and setting them on the path to eventual independence, employment and enhanced quality of life.

By providing families with access to such programs we will see direct benefits in family relationships, work opportunities and family cohesion.

From a government perspective extension of existing funding (provided to mainstream childcare providers) to specialist early intervention services means greatly enhanced outcomes from an existing funding initiative.

Finally, the long term cost savings to the community are enormous, with estimates suggesting that each placement in early intervention can save, over the lifetime of the child, \$1.2 - \$2.0M (Jacobsen et al, 1998). This would equate to total annual savings of \$1B (based on 800 new diagnoses each year), at an annual cost to government of \$30M (based on 2 years of early intervention with Inclusion Support of \$19000 pa per child).

For these outcomes to occur the Australian Government needs to:

1. Recognise the importance of Early Intervention Programs for children with autism.
2. Provide equitable funding to high needs children attending an early intervention program as they would receive were they be attending a mainstream childcare centre.
3. Remove the cap on the number of placements within a service that can receive Inclusion Support Funding.
4. Increase the total funding allocated to the Inclusion Support Scheme.

Thank-you for the opportunity to comment.

Dr James Morton
Chairman, AEIOU
Father of Andrew, aged 7, who was diagnosed with Autism in 2001/

6. Bibliography

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