

Report outcomes

Autism in Victoria: An investigation of prevalence and service delivery for children aged 0–6 years

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La Trobe University Researchers: Autism Group

ASSOCIATE PROFESSOR DR SG CREWTER

MS MJ GOODYEAR

ASSOCIATE PROFESSOR DR EL BAVIN

MR ML LAWSON

DR SA WINGENFIELD

Associate Professor Dr DP Crewther

Table of contents

Acknowledgements	3
Background to current project	6
What is autism/autism spectrum disorder	6
Major findings	6
Recommendations	7
Prevalence in Victoria 2002	8
Family and service provider methodology	9
Review of provisions in Victoria	11
Community costs in Australia 2002	13
Major recommendations: empowerment for parents and children in Victoria 2002	16
Recommendations elaborated	18
Regional central intake system	20
Family support coordination	20
Assessment/diagnosis	21
Early intervention services	21
Mentoring of generic services by autism-specific service providers	24
Regional coordination of support programs	24
Community education	25
Conclusions	25
References	26

List of figures

Figure 1 Empowerment through early intervention	18
Figure 2 Proposed model of service delivery for early intervention in Victoria	19
Figure 3 Coordination of services and mentoring of all early intervention services by autism-specific service providers	23
Figure 4 Earlier detection/referral of Autism within the community	24

Background to current project

This study reviewed international research on prevalence, knowledge and service delivery for young children (0–6 years old) with autism or autism spectrum disorder (ASD). The key objectives included:

- estimating prevalence in Victoria of autism (or potential ASD) in young children (aged 0–6 years)
- analysing current literature, trends, issues, service delivery and best practice models
- reviewing current diagnostic tools and assessment processes
- analysing current service needs and options for Victoria
- recommending coordinated and integrated service approaches, to support families caring for a child with ASD.

What is autism/autism spectrum disorder?

Autism or ASD is a neuro-developmental disorder, apparent from early childhood. It lasts throughout life, without any known cure or permanent treatment—at this stage. Autism is neither an acquired disease, nor a mental health problem in the true medical sense.

Autism distorts the way a child sees and interacts with others in the world. It is a complex and puzzling disorder, affecting the quality of life of people with ASD and their families throughout their entire lifetime. Autism is associated with deficits in social-emotional interactions, social communication and language, and inflexibility of thought and motor behaviours. Autism occurs in every social class. Symptoms are often compounded by intellectual impairment and learning disabilities, but not by any change in physical appearance.

ASD is defined behaviourally. It usually arises from anomalies in brain development early in pregnancy. Symptoms often coexist with other genetic and medical conditions and are associated with higher than average rates of disorders such as epilepsy, attention deficit hyperactivity disorder, cerebral palsy, obsessive compulsive disorder, bipolar disorder, and anxiety disorders and depression (Attwood, 1998; Wing, 1997).

Major findings

The major findings of this project are as follows:

- Best practice procedures throughout the state need to incorporate a family-based approach, driven by the individual needs of the child and their family.
- A lack of information about available services, long waits for formal assessment and limited access to early intervention are a source of frustration and distress for parents, particularly in rural areas.
- Centralised coordination of all regional services and ongoing family support were identified by parents as critical service needs.
- All service providers included in the project were conscious of the need for more specialised training in the area of ASD, by professionals with experience and expertise in the field.

- Ongoing community education and formal training for professionals working in the child development area needs to be addressed.
- There is overwhelming recognition of the need for a statewide policy of service coordination, in order to provide effective early intervention.
- The prevalence of ASD in Victoria is 27 per 10,000 children aged 0–6 years. This is comparable to international figures.

Recommendations

Basic assumptions underlying the recommendations

1. The statewide system should be designed to allow adequate access to the appropriate intervention services and support, to deliver timely assessment and intervention strategies throughout metropolitan and rural Victoria. This does not necessarily require a long-term service response in one program.
2. Services should be available to all children with ASD as early as possible. They should be directed at ensuring optimal ongoing social, communication, behavioural and educational opportunities for the child, together with ongoing, appropriate support for the family.

Recommendations include:

- a continuum of coordinated services at the regional/local level
- timely, effective early intervention for children in Victoria with probable or diagnosed ASD
- changing families' and providers' perceptions, to see that intervention can be effectively provided across a service continuum, rather than through a 'placement' in a centre-based specialised program
- empowering the family (through education, training and support), enabling them to work in partnership with professionals to facilitate optimal developmental opportunities in the child's natural environment (home, preschool and so on)
- family support coordination driven by the individual needs of the child and family
- a range of developmentally appropriate program options for each child and family
- educating service providers and the wider community about the needs of children with ASD and their families
- regular and objective evaluation of services and promotion of evidence-based practices.

Prevalence in Victoria 2002

Methodology

In order to estimate the prevalence of ASD in Victoria, all public and some Applied Behavioural Analysis (ABA) program providers delivering intervention services for children with ASD or probable ASD (201 in total) were systematically contacted. They were asked to provide information on the number of children currently attending their services that had either a diagnosis of ASD, or would most likely receive a diagnosis. Figures were then collated on the basis of Department of Human Services geographic regions. Numerical estimations of prevalence were only made for areas in which all service providers responded, and for whom all data were included.

The figures represent the most valid estimate of the number of children with a formal or informal diagnosis under the autism spectrum, across these regions. Areas in which reporting was incomplete were excluded, on the basis that it is impossible to estimate the number of children with ASD currently unidentified. Furthermore, there is no evidence indicating that the missing areas would provide different results. Estimates of findings from three of the nine departmental regions were pooled, to determine the prevalence figure. As both metropolitan and rural regions have been included, the prevalence reported is believed to represent a valid estimate across the state, as at July 2002. However, it is acknowledged that these numbers include few children with ASD who are assessed as having 'high functioning skills'.

Findings

- The prevalence rate of diagnosed ASD or suspected ASD in Victoria as of June–July 2002 in the 0–6 year age cohort of children is estimated at 27 per 10,000. Of these children, only 5 per cent are currently considered to be either high functioning, or have Asperger's Syndrome.
- As expected, ASD prevalence is approximately four times greater in males than females in Victoria.
- This figure represents a significant increase in reported Australian rates in the last ten years. Wing reported a prevalence rate of 19 per 10,000 for children with ASD in 1997.
- ASD was the most commonly reported (56 per cent) formal or informal diagnosis, rather than autism or Asperger's Syndrome.
- Thirty-four per cent of the reported cases currently attending early intervention therapies (or programs) had no formal diagnosis.
- Paediatricians comprised the largest referring group to early childhood intervention services, at 29 per cent.
- The second largest (22 per cent) source of referrals to early intervention service providers was from parents and families, highlighting the need for community and professional child care worker education on the early signs of autism.

Family and service provider survey methodology

Following approval by the La Trobe University Human Ethics Committee, focus groups were conducted with parents across the state and interviews were carried out with service providers to ascertain issues relating to the provision of early intervention services for children with ASD, aged 0–6 years. Seven parent-based focus groups were conducted and 40 early intervention service providers were interviewed. Most Department of Human Services (DHS)–Specialist Children Services (SCS) teams, Child and Adolescent Mental Health Services (CAMHS) teams and autism-specific and generic early intervention service providers in all regions were interviewed.

Two surveys were developed, based on the issues identified in the focus groups, interviews and literature survey. Surveys were sent to all service providers, to distribute to the Victorian families on their books who were receiving (or waiting for) intervention services for their preschool aged child with ASD. The La Trobe University Human Ethics Committee prescribed this method of distribution. Thirty service providers and 262 parents responded to the survey.

Effects on family

Families replying to the survey and parents participating in focus groups indicated that ASD induced undue stress in the family, either from birth or within the first 18 months. Family stress was generated by the child's behavioural characteristics (such as anti-social behaviours, temper tantrums, lack of communication, poor eye contact, repetitive motor behaviours) and the difficulties encountered in seeking professional help and assessment. Not only did many parents report difficulty in determining the source of their child's unusual behaviours, but difficulty with the professionals to whom they *'turned to for help, who were often inexperienced and in many cases unaware of recent developments in assessments and diagnosis'* and *'the feeling of lack of control regarding their child's future'*. The usually normal appearance of the child often led to professionals seeing the problem as either *'one that the child will grow out of in time'*, or one associated with parenting: *'I found I was treated like a neurotic mother in my first attempt of accessing help and diagnosis'*. (Details of parent comments appear in the full report).

Families from rural areas emphasised that the problems generated by having a child with ASD were exacerbated by geographic isolation and the frequent lack of formal and informal support systems nearby.

Findings

- Fifty per cent of mothers in the sample reported being full-time housewives. The most common occupations amongst fathers were trade occupations including mechanics, builders, carpenters (13 per cent) or in management (14 per cent). One third of the entire sample reported an annual income under \$30,000. Sixty-three per cent reported spending between \$1,000 and \$10,000 per year and 9 per cent reported spending more than \$40,000 a year on accessing additional services for their preschool aged child.

- Twenty-eight per cent of parents reported another family member with ASD.
- The time between assessment and diagnosis in Victoria averages between three and six months. The average age of the child on completion of the assessment and diagnosis phase is 40 months. Assessment availability is further restricted in country areas, with a waiting time for formal assessment and diagnosis as long as two years in some areas.
- Only 25 per cent of parents reported having an interim worker or telephone contact to assist the family while awaiting services and diagnosis. Most suggested such a service would have facilitated access to intervention services and helped address stress and anxiety associated with this time.
- In rural areas such as Horsham, Hamilton, north-western Victoria and parts of Gippsland, allied health services (private and public) are the sole providers of specialist services to these children.
- Sixty-one per cent of parents reported accessing early intervention (especially speech therapy), prior to final diagnosis.
- Thirty-four per cent of parents believed that the lack of access to a 'placement' in a specialised early intervention program would have negative effects on the development of their child.
- Forty-eight per cent of parents felt that their child was not receiving adequate intervention. They requested more hours/days of intervention, lower staff/child ratios and autism-specific services.
- Many parents also reported difficulty in finding someone prepared to mind the child or give respite, even for a short time.
- Forty-nine per cent of parents pay fees toward the cost of government funded early intervention programs.
- Although 94 per cent of the respondents get a Carer's Allowance and 91 per cent of children are on Health Care Cards, many parents commented on the frustration of having to have their child reassessed by a GP every six months, to meet Centrelink's six-monthly review policy. Parents perceive this as indicating a lack of community awareness of autism as a lifelong problem.
- Many parents commented that some professionals working with young children seem not to have current information that would assist them in detecting children who at risk of ASD.

Review of service provision in Victoria

Key issues raised by service providers include difficulties with staff recruitment and retention of those with specialist experience in working with children with ASD, inadequate provision of professional development, lack of community education, knowing about 'best international practice' and implementing strategies that are most appropriate for the child with ASD. Many services reported that their staff, although dedicated, eventually burn out and then seek employment in higher paid occupations.

Findings

Staffing

- Seventy per cent of service providers indicated they were able to recruit qualified staff experienced in working with children with ASD.
- Difficulties in staff recruitment were identified by some service providers, who reported waiting up to six months to fill a specialist position with experienced staff.
- Overall, service providers considered that it was very important (4.2 on a scale of 5) to employ staff with previous experience with children with ASD.
- Nearly all service providers surveyed (91 per cent) stated that they provide ongoing training for staff. However, less than half of these (43 per cent) offered secondary consultation or community education sessions to other service providers.
- Adequate training and support for staff in rural and remote Victoria was identified as an ongoing concern to be addressed.

Service delivery

- Fifty per cent of service providers responding to the survey offer services throughout the year and 50 per cent report operating on a Department of Education and Training school schedule.
- Fifty-two per cent of service providers report financial difficulties in providing the same level of service across the whole year and request more funding to provide continuity of services throughout the year.
- Eighty-six per cent of respondents were able to provide services for children provisionally diagnosed with ASD.
- Sixty-six per cent of service providers were able to see families within three weeks.
- Forty-two per cent of service providers were able to commence services within the first three weeks.
- Service providers indicated that they are offering services in addition to government funded services, to children and their families not able to access services in 2003.
- At 1 December 2002, three service provider respondents indicated a total of 48 children were waiting for services with their program. The providers acknowledged that some of these children might be on more than one waiting list.

- Approximately half of the service providers surveyed believed they currently demonstrated 'best practice' in early intervention service provision for the child with ASD. Components of 'best practice' included:
 - a client and family-centred approach
 - working with the family to determine service and supports agenda
 - immediate intensive intervention for the child with ASD
 - providing ongoing reviews of treatment options, according to family and child needs.
- Seventy-two per cent of service providers offered advice and secondary consultation to other service providers regarding early intervention services.
- Sixty-seven per cent of service providers allow parents to observe teaching staff, 43 per cent allow parents to participate in centre-based learning sessions and 33 per cent encourage parents to train alongside teaching staff.
- Eighty-four per cent of service providers currently measure outcomes in relation to their service provision, by reviewing goals set within the family service plan.
- Service providers varied regarding their perception of optimal hours for a child accessing their service. Thirty-seven per cent of service providers believed 2–4 hours a week of early childhood intervention services was optimal. However, a further 32 per cent of service providers believed that 6–10 hours a week was optimal.
- Ongoing planning and development of services for children with ASD is conducted by 38 per cent of the service providers surveyed. Issues for ongoing planning and development included:
 - improving access to the service
 - developing clearer strategies and measurable outcomes
 - expansion of service to accommodate growing needs
 - examining linkage and integration within the community.
- Victorian service provider respondents most frequently reported that the outcomes for children previously utilising early childhood intervention services included special education in a specialist school. Mainstream education with the assistance of an integration aide was the next most common outcome. Mainstream schooling without the assistance of an aide was reported as the least common outcome for a child with ASD, following early intervention.

Community costs in Australia 2002

Autism is a lifelong condition. Without effective and timely early intervention, many parents and professionals believe that a large percentage of children with moderate to severe autism will never attain adult independence.

One study in the US found that when schools invest about US \$3,000 for one year of preschool education, they immediately begin to recover their investment through savings and special education services see <http://www.kidsource.com/kidsource/content/early.intervention.html>).

The estimated Australian cost of supported accommodation or institutionalisation from 18 years of age for a person with autism is approximately \$109,000 to \$150,000 per annum for 50 years—an average of AUD \$3.75 million throughout life (figures drawn from [Autism Behavioural Intervention Queensland](#) Inc website). Thus, effective early intervention is readily justified from the viewpoint of social and economic concerns.

This estimate does not include additional costs of raising a child with autism up to 18 years of age. These costs would include extra child-minding and respite, and possibly costs associated with loss of income for the primary caregiver, costs for stress and emotional strain for children and families and loss of quality of life for all.

A document recently presented to the 2002 Commonwealth Senate Inquiry estimated service cost for a preschool age children with autism in ACT to be \$19,254 per year.

Rationale for early intervention for children with autism in Victoria

Early intervention for ASD refers to one or more services and supports—communication, social and behavioural therapies initiated early in childhood in an effort to minimise the impact of neuro-developmentally impaired behaviour. It does not refer to services in a specialised early intervention program.

Early intervention has been demonstrated to enable children to receive the best possible start for their educational training, health and social wellbeing (US National Research Council, Division of Behavioural and Social Sciences and Education, June, 2001) and to support families in optimising development appropriate behavioural management techniques (Stone and Yoder, 2001).

The parent and service provider survey and focus groups indicate that parents/care givers and service providers believe that early intervention is imperative if the child's social and intellectual impairments are to be minimised. In fact, the most often repeated and most distressing concern, inciting the greatest anger and frustration expressed by parents/carers/service providers, was the inability to access "*immediate early intervention*" for their child.

The question of how the impact of autism can be alleviated for the betterment of the child and his/her family—and how lifetime care costs can be reduced—is in the best interests of all in the community.

Best practice: early intervention

'Best practice' early intervention refers to the most universally accepted consensus of features that achieve the most effective outcomes.

Worldwide 'best practice' currently indicates that features of effective early intervention must be directed at both:

- enabling the child with ASD to eventually lead a more satisfying and more independent life
- educating and empowering the parent/carers of the child to support the child and improve quality of life for all the family.

Buckman ([Indiana Resource Center for Autism](#) website) has identified the following features of best practice:

- curriculum which focuses on child's ability to attend to relevant aspects of the environment, develop verbal and motor imitation, develop language comprehension and functional communication, develop social interaction with non-disabled peers and learn appropriate toy play skills (Dawson and Osterling, 1997)
- family education and training, emphasising parental skills (Dunlop and Fox, 1996)
- a focus on generalising and maintaining learned skills (Horner, Dunlop and Koegel, 1988)
- use of functional behavioural assessment to identify situations associated with problem behaviour, as a precursor to modifying situations and teaching alternative behaviours (Carr *et. al.*, 1994)
- development of educational settings to capitalise on the ability of the child with ASD to respond to visual structure, routines, schedules, and predictability
- sufficient intensity and frequency of intervention sessions (with an in-home training component or family training component to complement centre-based program)
- individualised programs, delivered over time in a coordinated manner by professionals and family members.

More specifically, Wetherby and Prizant (2001) recommend the following, based on their own research, for any intervention program:

- Focus on what the child *is* doing, not what the child is *not* doing (that is, on the child's interests and strengths, not limitations).
- Recognise the relevance of the child's conventional and unconventional behaviours for communication and interaction.

Family-centred practice

Family-centred practice, as defined by Dunst and colleagues (1997), is a particular approach to intervention that aims to empower families by increasing their understanding of the situation, at the same time as it addresses the immediate need of the child. Such empowerment then becomes the primary focus, aimed at strengthening and supporting the functioning of the family unit as a whole. A family-centred, child-driven intervention perspective then has specific applications for service coordination and integration. This type of service model is supported by the growing body of evidence that suggests that different approaches to mobilising resources are likely to have different and more generalised effects for individuals, which persist through the

child's transition to school years. Such approaches are more formally developed in the UK and Canada, and more recently in New Zealand.

Under this model, early intervention is operationalised as a 'particular set of functions for linking resources and families' (Dunst and Trivette, 1994), such that the role of the expert may shift more towards mentoring and educating of interested others (parents/caregivers and the community in general), rather than just giving intervention to one individual child.

Major recommendations: empowerment for parents and children in Victoria 2002

There is now clear evidence from best practice that the education and training of parents in a short intensive program, initiated as early as possible, will significantly increase the likelihood of the child with ASD achieving his/her potential, as well as empowering the family by helping them take some of responsibility for intervention.

Is immediate early intervention possible for every child?

For many families, it takes some time to come to terms with the diagnosis of ASD, the associated grief issues and the inevitability of the need for some specialised early intervention services. Once this period is over, parents apparently focus on trying to facilitate their child's access to a formal program. Many parents appear to be disregarding the fact that they are probably already accessing some individual services and supports, as they await services in a more formally organised program. Most families reported, *"desperately needing to find a place in an early intervention program as quickly as possible"*.

There is currently not sufficient funding to ensure immediate access to early intervention programs for all children with ASD. As the earlier detection of ASD increases in the community, there will be an even greater need for more funding to provide effective and timely early intervention.

A new approach to access to effective service

Underlying our recommended model of service delivery are these core assumptions:

- i. All children with ASD or probable ASD must receive immediate and effective early intervention services, aimed at their additional needs in a developmentally appropriate manner.
- ii. Parents of children with ASD or potential ASD need immediate access to information and education about the disorder and the range of program options available.

Hence, the following recommendations need to be considered and addressed in service planning and development:

- i. The formal family support services must always work in partnership with the family and have access to a system of up-to-date information.
- ii. All families of children with ASD or potential ASD need informal and formal support services, providing information and facilitating access to services or programs available in the local region and appropriate for each developmental stage in the particular child's life.
- iii. Service provider partnerships between families and the Family Support Coordinator (FSC) will only work if trust is established. This requires well informed staff, with access to current information relevant to the child and family situation, together with mentoring by specialist teachers/therapists with expertise in autism for local early intervention staff who come in regular contact with the child.

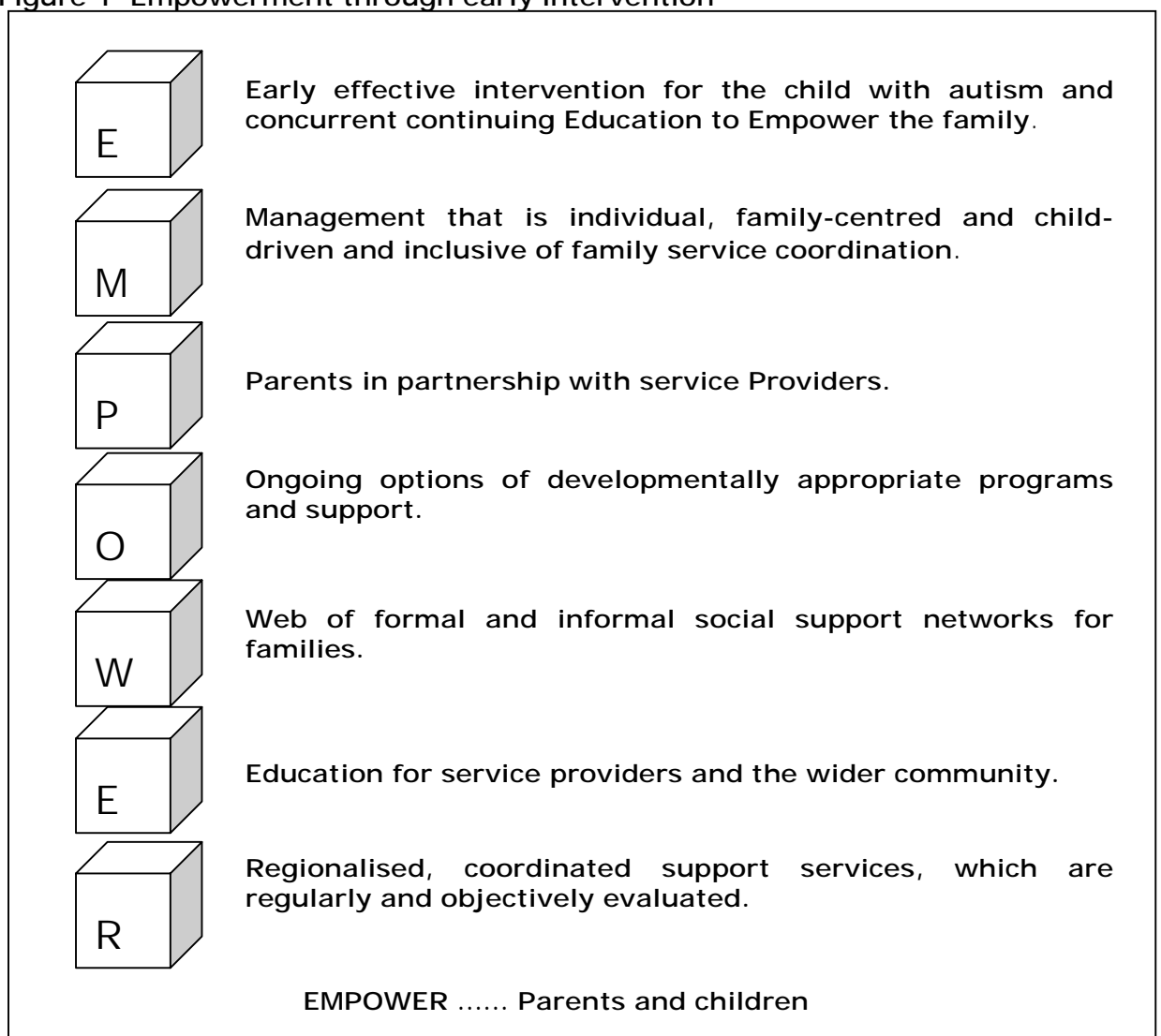
It is acknowledged that the times of greatest need for child and parent are immediately after identification of a probable diagnosis and following formal diagnosis. Thus, the earliest intervention should be delivered by experienced personnel who can provide the initial intensive effective support necessary for the child, and the education and training of the parents to allow them to work in partnership with a FSC. Whether a child initially needs an individual or group program, or a combination of these, should be the joint decision of parents, the FSC and autism-experienced staff.

Decisions about future appropriate programs and support should rest with the parents, but it is envisaged that parents would prefer to share decisions with therapists or staff with expertise in autism. Education for parents about their child's condition and possible intervention strategies—and involvement in all decisions affecting their child's needs—are expected to improve parental confidence and parenting skills. Such empowerment will effectively prepare families to cope on their own when the child is in transition to the potentially less supportive school environment.

Recommendations elaborated

Figures 1–4 illustrate how the recommendations in this report might best be achieved. Each figure is followed by a short commentary.

Figure 1 Empowerment through early intervention



The acronym EMPOWER captures the conceptual recommendations in the report. Early intensive effective intervention that involves and educates parents is mandatory. However, the type of intervention at different times in a child's development will change, as a function of individual assessment of the particular child and their family's needs and decisions. This information has to be maintained centrally in each region to

guarantee families' and service providers' immediate access to past histories and new developments.

Figure 2 Proposed model of service delivery for early intervention in Victoria

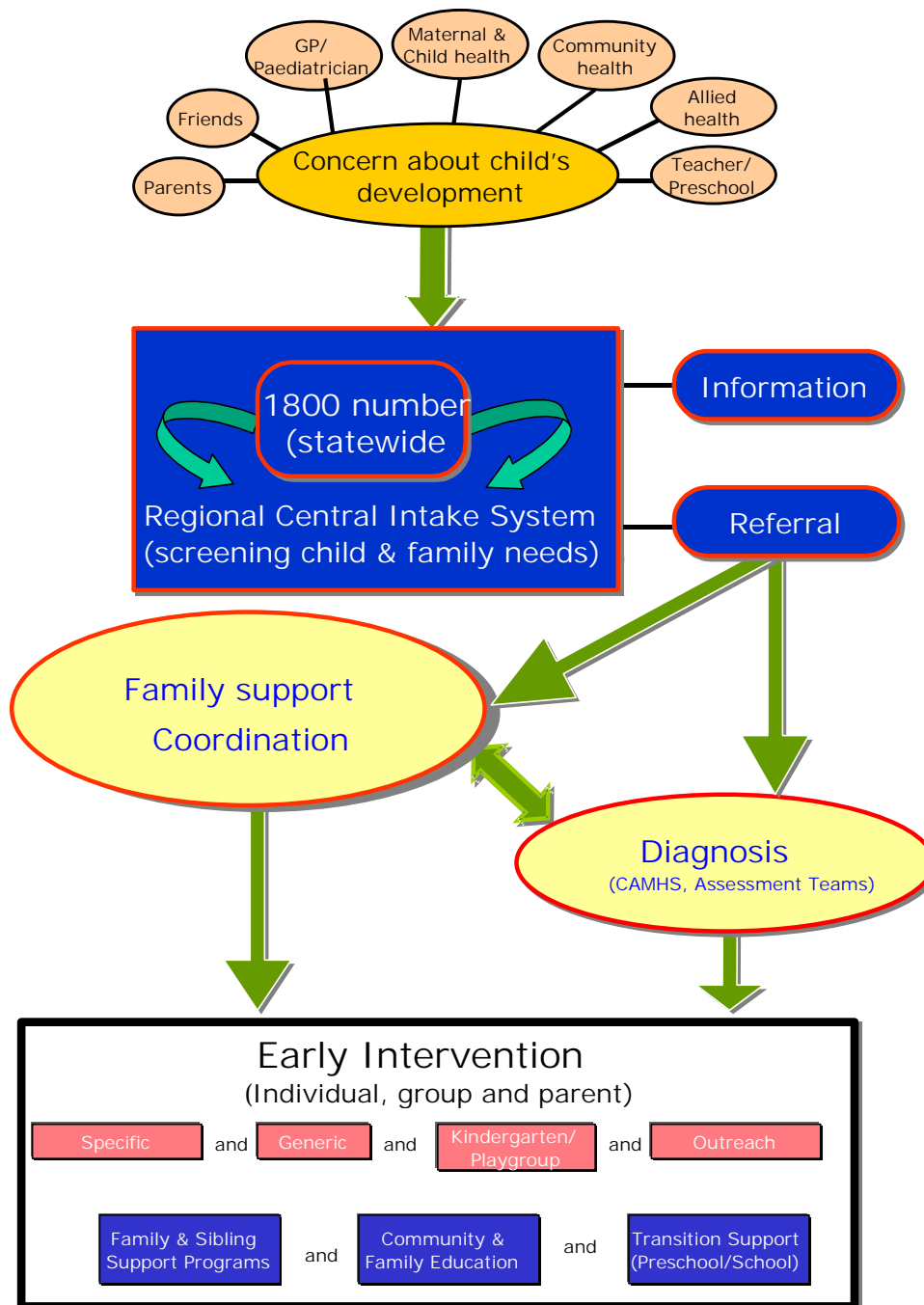


Figure 2 represents a number of proposed recommendations taken from a review of the literature on early intervention, interviews with service providers and the results of the parent and service provider surveys. It incorporates a number of 'effective' components of service delivery already implemented in the field.

Regional central intake system

Service coordination emerges as the most pressing organisational need. A regional central intake system will achieve this goal. Such a system is already in operation in a number of regions. It should conduct a needs assessment of the child and family and provide information to families upon request. Depending on needs, referral to short-term early intervention and/or family support coordination can be arranged. This system should coordinate with all early intervention services.

Benefits:

- There is a single, highly visible and easily accessible point of contact to deal with initial enquiries about a developmental delay/disability.
- Assessment can be undertaken promptly, to identify the immediate and ongoing needs of the child and family.
- Decisions regarding timely access to effective early intervention are based on availability and location (particularly important in rural areas).
- Family support will be available as early as possible.
- There is better management of demand for early intervention:
 - database of clientele can easily be generated
 - demand for services can be accurately measured
 - central records can be kept on the availability of services.
- It allows a coordinated approach to service provision, because all service providers within the region participate in implementing and managing requests for assessment and early intervention.

Family support coordination

The type of family support coordination/case management needs to be allocated at central intake and be an ongoing support to the family, throughout the process of diagnosis and intervention.

The case coordination component should aim to incorporate the following:

- family support coordinators providing ongoing family support and monitoring the changing needs of the family
- offering information or information sources on the child's disorder, at the request of the family

- details of regional/local universal early childhood workers and specialist staff, to link with the most appropriate service to meet the developmental needs of the child and the needs of the family.

Benefits:

- An easily accessible support person who has knowledge of the regional services and an understanding of the family's history and circumstances.
- The ability to address the immediate needs of the family and provide ongoing monitoring of changing needs and circumstances.
- Providing information to families about ASD and about the 'workings' of the early intervention sector.
- Better liaison with service providers, to ensure effective communication and coordination of services to support the child and family.

Assessment/diagnosis

The assessment/diagnosis process should happen as early as possible, to minimise waiting time for the child and family. Formal diagnosis needs to be conducted by a multidisciplinary team, covering communication, socialisation, and language—including rigidity of thought, motor behaviours and other ritualistic behaviours of the child. The multidisciplinary team should be comprised of a psychiatrist/paediatrician, psychologist and a speech therapist. A behavioural assessment conducted over a number of sessions and in different environments is desirable.

Feedback needs to be conducted with all relevant members of the family (including the extended family) and needs to include details of the child's condition (both verbally and in writing), information about ASD or sources where parents can obtain the information, and counselling where appropriate. Many families complained of the lack of compassion, knowledge and feedback provided by current assessment teams. The feedback report needs to inform parents of appropriate options to help their child attain his or her potential.

The professional expertise needed for formal diagnosis could be accessed more easily and possibly more effectively, if provided by the experienced personnel of specialist services. This system has already been implemented by Gateways in Barwon–South Western Region and could be provided by other specialist services, such as Irabina in the Eastern Metropolitan Region, Kalparrin in the Northern Metropolitan Region or Pinarc in the Grampians Region.

Early intervention services

An early intervention program needs to provide initial intensive services, to establish basic social and communication skills and other behaviours necessary for independent daily functioning.

Early intervention may be provided within an ASD-specific program or a generic developmental delay program—at home, centre-based, or both. Intervention must also include social skills training, such as delivered by a playgroup or kindergarten (with support worker if necessary), depending on the age of the child.

Families awaiting commencement of the appropriate longer-term program require short-term intervention as part of an outreach service, beginning immediately after **the needs** assessment initiated by regional intake. This may include parent training and education about ASD/developmental delay, and for the child, speech therapy and behavioural management strategies.

Continual family support and monitoring of the changing developmental needs of the child and family are essential. Opportunities for parent education on ASD and for establishing parent support networks are also very important. Additional programs to support siblings of children with ASD, and support for transition to mainstream kindergarten or entry into the education system, should also be a necessary part of the early intervention program.

Benefits:

- empowers the family to implement and maintain behavioural management strategies in the home environment
- aids parental understanding of ASD and the child's behaviour
- implements programs and support as early as possible, to promote optimal development of the child and provide support to the family.

Figure 3 Coordination of services and mentoring of all early intervention services by autism-specific service providers

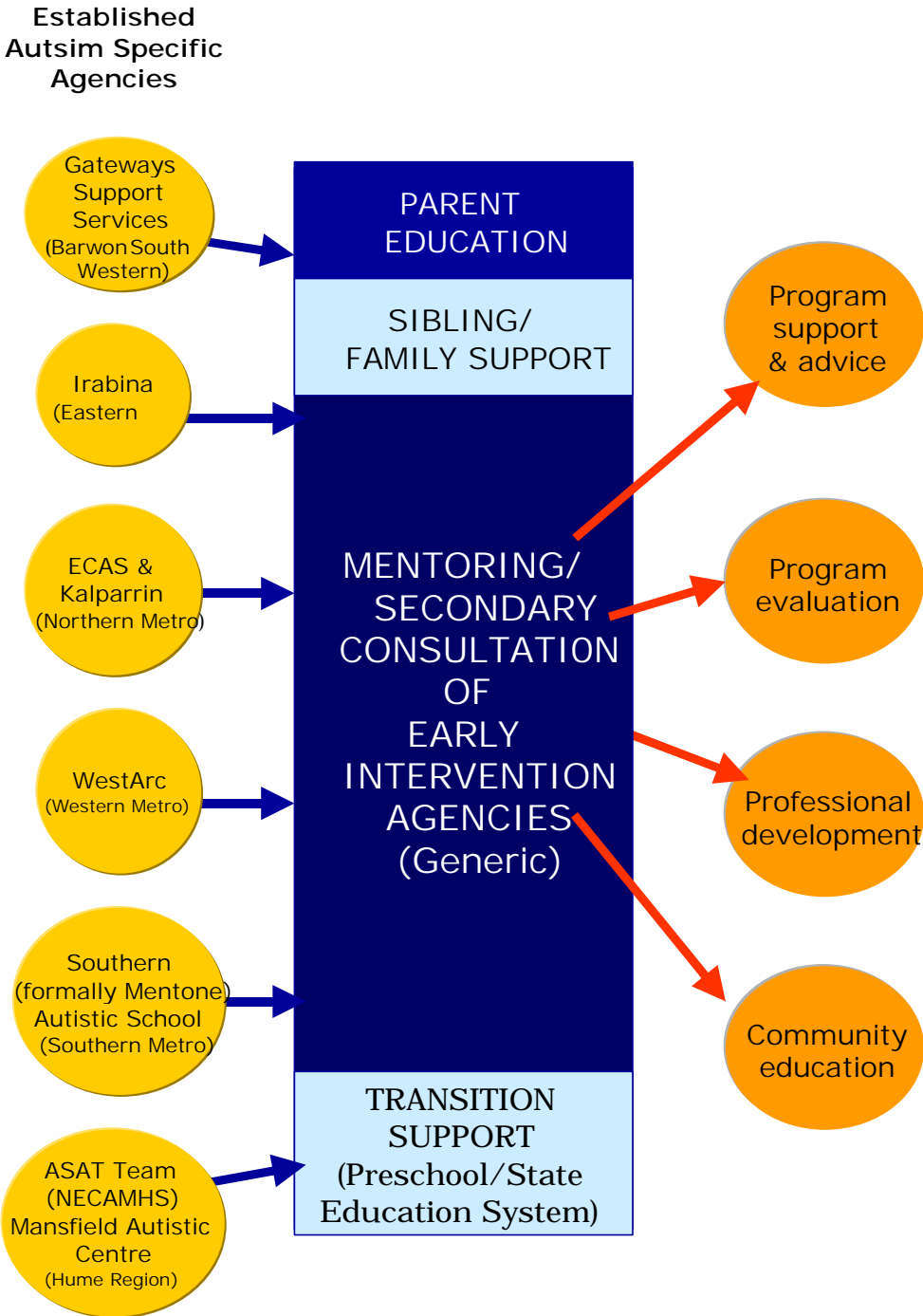


Figure 3 represents a model that will encourage mentoring and continuing education by specialist service providers for new staff, for less experienced service providers and for the community in general.

Mentoring of generic services by autism-specific service providers

Generic services would benefit from consultation with autism-specific services for program support and advice, program evaluation, professional developmental and community education on autism. In particular, mentoring by autism experts for staff within local generic early intervention services and preschools will increase the likelihood of earlier detection. Mentoring by autism-specific service providers could be implemented on a regional basis, where an autism-specific service is in operation. Consultancy across regions will be necessary, where only generic early intervention services are operating.

Regional coordination of support programs

Support programs—including the education of parents, sibling support programs and transition support programs—could be coordinated at a regional level by existing autism-specific service providers. The provision of education and support programs by autism-specific service providers could be implemented on a consultancy basis within each region and outsourced to regions without an autism-specific agency. Thus, up-to-date information specific to ASD can be disseminated to the field, as requested.

Figure 4 Earlier detection/referral of Autism within the community

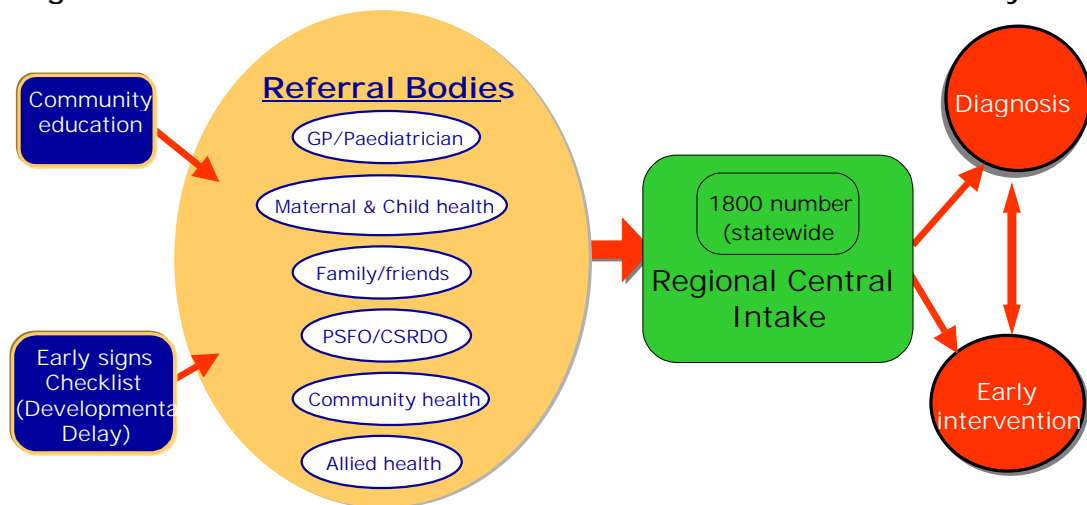


Figure 4 represents an organisational model that assumes greater community and professional education will increase the likelihood of earlier ASD detection. In many

cases, sufficient staff and expertise already exist in each region for the foremost service provider (a suggested mentoring organisation) to do many of its own cross-disciplinary formal assessments, thus drastically reducing the time between application for assessment and formal diagnosis.

Community education

Community education is central to the early detection of ASD. Education and up-to-date, easy-to-understand information about autism must be made available to referral bodies such as general practitioners and paediatricians, maternal and child health nurses, preschool field officers within preschools, children's services resource and development officers within childcare centres, professionals within community health centres, and other allied health professionals. These people are usually the initial professional contact for parents concerned about their child and they are already in a position to monitor the child's development. A readily available fact sheet outlining early signs could assist in constantly reminding professionals of the features of ASD.

As indicated in the parent and service provider survey results, community education is necessary:

- to enhance the earlier detection of ASD
- to promote earlier referrals to assessment service providers
- to develop a greater awareness and social acceptance of the realities of the disorder and its presenting features, rather than the distressing attitude of "*that child needs a good smack!*".

Conclusions

The research literature is consistent with the findings of our survey, emphasising that a move towards earlier, more coordinated, family-centred and child-directed early intervention services is absolutely essential, if children with ASD in Victoria are to be given maximum opportunity to reach their potential. Such services also perform an essential role in empowering families and to minimising stress for those associated with children who have ASD.

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