

Helping people with dyslexia: a national action agenda

Report to the Hon Bill Shorten, Parliamentary Secretary for Disabilities and Children's Services, from the Dyslexia Working Party:

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Introduction

During 2008 the Hon Bill Shorten, Parliamentary Secretary for Disabilities and Children's Services, met with representatives from dyslexia interest groups who expressed concern that dyslexia is not recognized as a specific disability under the Disability Discrimination Act 1992 and that the education and employment systems do not recognize or support people with dyslexia.

Following these meetings the Parliamentary Secretary requested the FaHCSIA convene a roundtable Forum to discuss these issues.

This Dyslexia Stakeholder Forum was held at Parliament House Canberra on 16 June 2009. The Forum consisted of 24 people who were scientists in the areas of reading or learning disabilities, technologists, people with dyslexia, clinicians and practitioners, or representatives from DEEWR and FaHCSIA. It was decided that a representative Working Party of 8 Forum members should be formed, charged with the task of writing a report proposing a national agenda for action to assist people with dyslexia.

The Working Party consulted widely and in particular benefited from comments on a draft report that were received from the following authorities (all of whom have expressed very strong support for the recommendations we have made):

- AUSPELD (The Australian Federation of Specific Learning Difficulty Associations)
 - LDA (Learning Difficulties Australia)
 - ALDA (The Australian Learning Disability Association)
 - Speech Pathology Australia
 - The DDOLL (Developmental Disorders of Language and Literacy) network, which was established with funding from the Australian Research Council.
- Sir James Rose, author of the Rose Report on Dyslexia commissioned by the UK Government.

A draft report was also distributed for comment to members of the Forum on December 7 2009.

The draft report was revised in the light of these comments and the final version of the report (the present document) was submitted to the Parliamentary Secretary on January 10 2010.

In this document we put dyslexia into context by first making some remarks about general levels of literacy in Australia and why they are currently a cause for concern. We then explain the difference between dyslexia and other forms of difficulty in learning to read, and point out the serious social, economic and personal consequences of dyslexia. We then provide 19 recommendations, each of which if implemented would reduce these social, economic and personal costs of dyslexia in Australia.

Is there a literacy problem in Australia?

The Council of Australian Governments (COAG) believes so. Its report entitled “National Agreement for Skills and Workforce Development: Baseline performance report for 2008”, dated 30 September 2009, made the following points:

- Relatively high proportions of working age Australians have literacy and numeracy skills below the minimum level COAG considers is required to meet the complex demands of work and life in modern economies—43.5 per cent for literacy and 49.8 per cent for numeracy.

- The proportion of the working age population with low literacy and numeracy skills decreases as socio-economic status improves. At a national level, 60.0 per cent of working age people in the most disadvantaged socio-economic areas have low literacy skills compared with 29.3 per cent in the least disadvantaged areas. The figures for numeracy are 66.2 per cent and 35.3 per cent respectively. The pattern is similar across all States and Territories.

These conclusions are based on data from a national survey of literacy standards carried out by the Australian Bureau of Statistics (ABS) in 2006. The ABS report of that survey specifically noted that 52% of Australians aged 15-19 had a literacy level that “was insufficient to meet the complex demands of everyday life and work”. Comparisons of the results of the 2006 ABS survey with the results of the immediately preceding survey (1996) revealed that literacy levels were lower in 2006 than in 1996.

There is independent evidence that literacy standards are currently declining in Australia. Reading ability of Australian children was measured in the OECD’s International Programme for International Student Assessment (PISA) assessment rounds in 2000 and most recently in 2006. Between 2000 and 2006 Australia dropped 4 places in the international ranking of literacy levels, being overtaken by New Zealand, Canada, Hong Kong and South Korea (reported by the chair of the Australian Curriculum, Assessment and Reporting Authority, Professor Barry McGaw, in his keynote address at the seminar *Effective Reading for All: National and International Perspectives* conducted by Learning Difficulties Australia (LDA) in Melbourne on 23 September 2009).

Why is there a literacy problem in Australia?

In 2004 the then Federal Minister for Education, Dr Brendan Nelson, commissioned a National Inquiry into the Teaching of Literacy (NITL)ⁱ which reported to him in December 2005. Amongst the findings of this report were the following:

- 50% of the 34 teacher training programs in Australia devoted less than 5% of the curriculum to teaching about reading.
- 60% of senior teachers considered the majority of beginning teachers were not equipped to teach children to read.

- The majority of beginning teachers reported that they were not confident about their ability to teach reading.
- Many beginning teachers themselves had limited literacy skills, and also lacked the metalinguistic skills needed for the teaching of reading.

The NITL Report made 20 recommendations aimed at improving the teaching of literacy. Unfortunately none of these was implemented. The Education portfolio was taken over by a new Minister. The recommendations of the report were put out to tender, which was won by the Curriculum Corporation, which produced materials that were distributed to schools. The Chair of the NITL, the late Dr Ken Rowe of the Australian Council for Educational Research, publicly repudiated these materials, pointing out that they did not incorporate a single one of his committee's 20 recommendations.

However, all is not lost. The Australian Curriculum, Assessment and Reporting Authority (formerly the National Curriculum Board) is drawing up a national curriculum for English which includes a specific focus on teaching reading and reading-related abilities in the early years of schooling. Current drafts of this curriculum document show that it is highly compatible with the recommendations of the NITL. For example, recommendation 2 of the NITL was:

The Committee recommends that teachers provide systematic, direct and explicit phonics instruction so that children master the essential alphabetic code-breaking skills required for foundational reading proficiency. Equally, that teachers provide an integrated approach to reading that supports the development of oral language, vocabulary, grammar, reading fluency, comprehension and the literacies of new technologies.

Consistent with this, the May 2009 ACARA document "Shape of the Australian Curriculum" states (p. 7) "Many students when learning to read need systematic attention to fundamentals like phonological and phonemic awareness, and sound-letter correspondences as well as the development of skills in using semantic and syntactic clues to make meaning". And at his keynote address at the LDA seminar (referred to above) the Chair of ACARA indicated that the National Curriculum would emphasize the teaching of phonological awareness, phonics and the alphabet in kindergarten and Grade 1, just as recommended by the NITL

State Departments of Education are also beginning to take actions that are consistent with the NITL recommendations. For example, NITL Recommendation 16 included the following:

The Committee recommends that a national program of literacy action be established to produce a series of evidence-based guides for effective teaching practice, the first of which should be on reading.

The NSW Department of Education has this year produced exactly these

kinds of guides to the teaching of literacyⁱⁱ.

The ACARA recommendations re initial teaching of reading, if implemented right down to individual classroom level, will be of great benefit to many Australian children who would otherwise have struggled to learn to read. Improved curricula delivered in a structured, sequential and explicit way, along with intensive intervention for those children struggling to keep up with their peers, will address the needs of the vast majority of students. But there will still remain a residue – perhaps as many as 5-10% of all children – who will still struggle to learn to read even if exposed in the classroom to best-practice evidence-based methods of teaching reading. The remit of our Working Party is to make recommendations about how best to help such children as well as the adults who were once such children.

The difference between “instructional casualties” and “people with dyslexia”.

A great deal of recent research has focussed on what happens when a school that has been using methods for teaching reading based on ideology rather than research evidence of efficacy switches over to adopting evidence-based methods. Many studies have documented rapidly-achieved and large increases in the reading competence of poor readers in such schools; these children soon achieve reading abilities commensurate with their grades. It follows that the reason why such children were reading poorly prior to the adoption of the new teaching methods in their classrooms was not something to do with the children themselves, but was because of the kind of reading instruction they had been receiving (the *California State Taskforce* (1999)ⁱⁱⁱ reported that "a significant number of children labelled learning disabled or dyslexic could have become successful readers had they received systematic and explicit instruction and intervention far earlier in their educational careers"; That is why the term “instructional casualties” has been used to describe these children.

But these studies have also shown consistently that a small but significant proportion of children do not catch up in reading no matter how sound and well-supported by evidence the teaching methods being used in their classrooms are. Although these students are likely to make some progress, they tend to improve at a much slower rate than their peers, and must work very hard even to achieve this. So these children are not instructional casualties, and therefore a different term to describe them is needed. It is these children whom we will term “children with dyslexia”.

Identification of dyslexia via this approach is referred to as the *Response to Intervention* Model (RTI). It has become widely accepted practice in the UK, the USA, and Canada:

"A good indication of the severity and persistence of dyslexic difficulties can be gained by examining how the individual responds, or has responded, to well founded intervention" (Rose, 2009).^{iv}

The model requires a three tiered approach to literacy teaching, intervention and assessment (see figure 1).

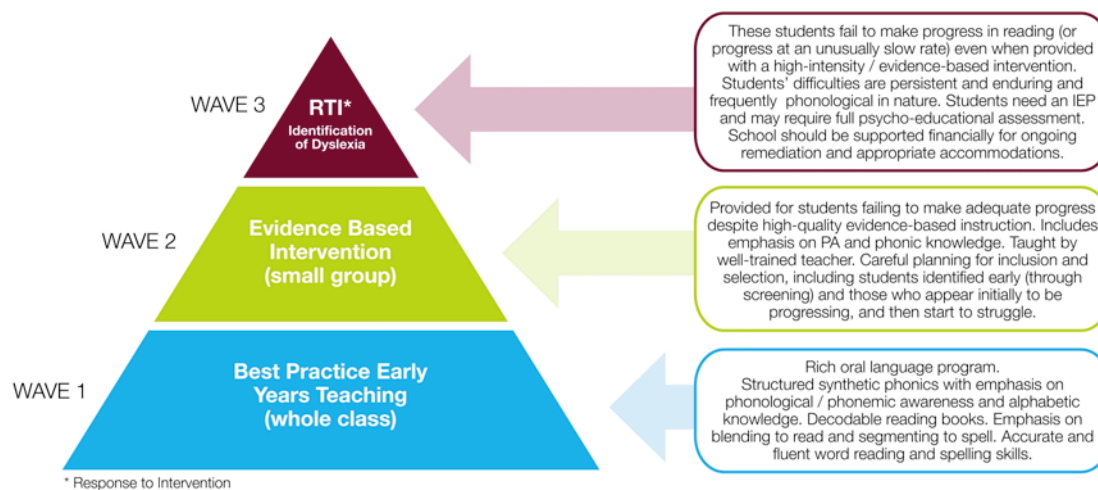


Figure 1. Identifying Students with Dyslexia within the Three Wave Model.

If the evidence-based literacy teaching approaches proposed in the National Curriculum are implemented right down to classroom level, this will be enormously beneficial to the children classified as instructional casualties, and so one would expect to see substantial improvements in the average literacy levels in Australian schools. But if that is all that is done, the children with dyslexia will benefit only to a small degree. They will continue to be left behind and the gap between these children and their peers will widen even further.

Our Working Party's job is to make recommendations as to what steps should be taken to address the needs of these individuals and so reduce the functional impact of dyslexia.

The economic, social and personal costs of dyslexia

Failure to learn to read despite receiving appropriate reading teaching has serious consequences.

Research has shown that such children are at serious risk of mental health difficulties^v especially depression^{vi}. Juvenile delinquency is more common amongst such children^{vii} as is dropout from school^{viii} and unemployment (Australian Bureau of Statistics data). People with poor literacy are less responsive to health education and use of disease prevention strategies, are less able to successfully manage chronic disorders such as diabetes and asthma, and incur significantly higher health care costs^{ix}. All these personal costs of dyslexia explain why a significantly higher proportion of people with dyslexia are likely to attempt suicide than adolescents with normal reading^x. And these personal costs of dyslexia explain why the final report of the National Health and Hospitals Reform Commission has identified that strengthening functional literacy is a key strategy

to improving health outcomes across Australia^{xi}.

These are just some of the serious personal costs of dyslexia. Dyslexia has serious social and economic costs too.

The incidence of dyslexia is much higher in the prison population than the general population: for example, a recent study reported that 53% of the inmates of Chelmsford Prison in the UK were dyslexic^{xii}

The UK House of Commons Science and Technology Committee in its report dated 18 December 2009 concluded that “the Government’s position that early literacy interventions are an investment that saves money in the long run is evidence-based”.

A report by Access Australia^{xiii} jointly commissioned by the Business Council of Australia and the Dusseldorp Skills Forum to test the merits of the economic case for increased policy emphasis on youth participation in education, training and employment reported that:

- Student achievement and better pedagogies in literacy and numeracy are fundamental to improving the learning capacity, employability and positive participation of young people
 - Boosting the proportion of young people completing school or an apprenticeship to 90 per cent by the end of the decade would increase workforce numbers by 65,000, boost economic productivity, and expand the economy by nearly \$10 billion (in today’s money) by 2040
 - Measures to increase school retention rates would also result in additional annual taxation receipts of \$2.3 billion (in today’s money) by 2040, reducing Budget deficits and helping to defray the cost impact of the ageing population.

In Australia at present, children and adults with dyslexia have no specified pathways to achieve diagnosis and support. In the education system there are few qualified to diagnose, and the wait time for school psychologists is up to a year. For adults, there is no process through Centrelink for support. Individuals therefore have to fund their own diagnosis and subsequent support. On a user pays basis, only the financially secure can afford this. This leaves pensioners, low-income earners, students and the unemployed with nowhere to go.

RECOMMENDATIONS

Our recommendations are about both reducing the impact of dyslexia on the approximately 5-10% of Australian children and adults who struggle with its daily implications and about the ways in which assistance can be provided earlier and more effectively (thereby preventing dyslexia from becoming as serious a condition as it does when left unattended). These recommendations are designed to improve both access and equity in the everyday lives of Australian children and adults currently struggling with this hidden disability. This can be achieved through:

- Officially recognizing dyslexia as a disability;

- Providing high quality literacy instruction;
- Providing school-based dyslexia resilience programs.
- Improving current teachers' knowledge, skills and understanding of learning to read and dyslexia;
- Improving training courses for future teachers;
- Enabling access to early assessment and identification;
- Providing appropriate support and accommodations, including the establishment of an Accessible Instructional Material Centre (AIMC) whose first task will be to facilitate the development of a national Accessible Instructional Strategy (AIMS);
- Establishing dyslexia-friendly schools and workplaces; and,
- Increasing community awareness of dyslexia.

Implementation of these recommendations would have two highly beneficial results:

- It would maximise the probability of successfully learning to read, and
- It would minimise the negative impacts of being unable to read

DEFINING AND RECOGNISING DYSLEXIA AS A DISABILITY

Recommendation 1 - Definition of dyslexia

There should be adoption at a national level of a working definition of dyslexia to allow shared language for productive discourse on the issue in Australia. Our proposed working definition, consistent with the definitions published by the British Dyslexia Association, the International Dyslexia Association/ National Institute of Child Health and Development, the International Reading Association, and the Rose Report on Dyslexia, is:

Dyslexia is a language-based learning disability of neurological origin. It primarily affects the skills involved in accurate and fluent word reading and spelling. It is frequently associated with difficulties in phonological processing. It occurs across the range of intellectual abilities with no distinct cut-off points. It is viewed as a lifelong disability that often does not respond as expected to best-practice evidence-based classroom methods for teaching reading.

Recommendation 2 - Recognition of dyslexia as a disability

There should be legislative recognition at both State and Commonwealth level of dyslexia **as a disability** as determined under the Disability Discrimination Act (1992). Dyslexia should be included under the special needs section of the Education Acts in each of the states as has now been instituted in NSW. This will require that additional disability funding becomes available.

Recommendation 3 - National Dyslexia Advisory Council

A National Dyslexia Advisory Council should be established. Its membership should include people with dyslexia, representatives from Australian peak dyslexia organizations, and national and international experts on dyslexia and learning disability.

Recommendation 4 - Compliance with the Act.

Commonwealth funding of all educational institutions should be contingent on demonstrated compliance with the Disability Discrimination Act 1992 (Amended in 2008), and the Disability Standards for Education 2005.

SCHOOLS AND TEACHERS

Recommendation 5 - Pre-service training

All teacher-training syllabi should include:

- Training in evidence-based reading instruction, shown through rigorous research to minimise the impact of dyslexia;
- Training in early screening / identification of students at risk of long term literacy problems, including dyslexia; and,
- Training in effective, research-based strategies that support students with dyslexia including: resilience development, use of non-print mediums, and presence of whole school dyslexia policies.

Recommendation 6 – Evidence-Based Teaching

- It should be ensured that appropriate teaching strategies, shown through rigorous, evidence-based research to be effective in developing strong literacy skills, are used in all Australian Junior Primary classrooms. This will assist in reducing the impact of dyslexia significantly.
- All schools should ensure that the three Waves of literacy provision are in place, are of a high quality, and are well-coordinated. In order to achieve this, schools should have access to the expertise of teachers with specialist skills in addressing dyslexic difficulties
- Provision should be made for close monitoring of students ‘at risk’ of dyslexia as well as those diagnosed with dyslexia
- Learning Support should be provided for those diagnosed with dyslexia through a written Support Plan that incorporates individual literacy teaching, resilience teaching, and classroom accommodations.

Recommendation 7 – In-Service Training

- Professional development programs should to be developed for all practising classroom teachers to assist them to identify and support students at risk of dyslexia.
- Existing in-service training courses provided by approved organizations should be officially recognized and funded.

Recommendation 8 – Specialist Training

Funding should be provided to universities and other approved organizations for the establishment of specialist accredited training courses to train practising teachers to identify and teach students at risk of dyslexia, such as those courses provided by Dyslexia Action UK.

Recommendation 9 – Dyslexia-Friendly Schools

- A national program should be established for the development and accreditation of ‘dyslexia-friendly’ schools involving specific inclusion (at all levels of policy and practice) of the needs of students who have dyslexia. (The British Dyslexia Association has a detailed model of such ‘dyslexia friendly’ schools).

- A funding scheme should be established to which schools could apply with a specific plan for making the school dyslexia-friendly. Schools already accredited as dyslexia-friendly could also apply to this scheme for funding to become consultants and PD providers to other schools and to become providers of assistance to dyslexic children in other schools.
- Clear guidance should be provided to schools on what appropriate provisions have become available for people with dyslexia.
- A national teacher dyslexia resource booklet should be compiled and distributed to all schools, similar to that produced by NZ Education Dept.

Recommendation 10 – Special considerations for people with dyslexia.

A diagnosis of dyslexia should entitle a student or adult to use a computer or laptop, with appropriate assistive technology programs installed, in class, in exams and in the workplace; and should also entitle students to additional time in exams, or to the use of a reader or scribe.

ASSESSMENT OF DYSLEXIA

Recommendation 11 – Dyslexia Assessment

- Access to early, systematic, dyslexia assessment should be available to all students identified by teachers as being at risk of dyslexia.
- Initial screening and assessment of such at-risk children to be undertaken within the school environment by a specialist teacher, followed by in-depth assessment of reading and spelling by an appropriately-trained psychologist, speech pathologist or other person with relevant qualifications.
- FaHCSIA should directly fund parents and adults to access dyslexia assessments provided by suitably qualified professionals.
- Full funding through Centrelink should be provided to parents on pensions or with health care cards, students on Austudy or equivalent and those on unemployment benefits.
- Professional development programs need to be developed for all practising school psychologists to assist them in the assessment and appropriate support of students with dyslexia.
- Recommendations arising from in-depth assessments should be fully supported by the school, training institution or workplace.
- The cost of dyslexia assessment, tuition and costs involved with accessibility such as alternate formats and specialist software programs should be added to the list of eligible expenses for the Education Tax Refund.

APPROPRIATE SUPPORT AND ACCOMMODATIONS

Recommendation 12 - Information booklet for families

A booklet for families and carers should be prepared and distributed which explains what new provisions for dyslexic children have been introduced.

Recommendation 13 – Accessible Instructional Material Strategy (AIMS)

An Accessible Instructional Material Strategy (AIMS) for primary, secondary and tertiary education should be established throughout Australia. This should be enacted through Federal legislation.

Recommendation 14 – Accessible Instructional Materials Centre.

The Federal Government should establish an Accessible Instructional Materials Centre (AIMC) as a matter of urgency.

Recommendation 15 - Assistive Technology

- Funding for the Print Disability Services Program should be increased, with the appropriate level of funding determined under the AIMS.
- An Assistive Technology Fund for Dyslexia should be established that provides assistive technology options directly to students around Australia.
- A national subscription to Bookshare should be funded by FaHCSIA.
- Publishers should be required by legislation to provide an electronic version of any educational text.

COMMUNITY AWARENESS

Recommendation 16 – Community Awareness

National support should be provided for initiatives that develop community awareness and understanding of dyslexia, such as:

- Funding should be provided for existing Dyslexia help lines and support programs.
- Support for a Dyslexia Week should be developed.
- A mentor system by successful people who have dyslexia should be established.
- A Dyslexia section on the FACHSIA Raising Children website should be developed.
- Clear guidance should be provided to families on what appropriate provisions have become available for people with dyslexia.
- Media coverage of what assistance people with dyslexia are entitled to receive should be fostered.

EMPLOYMENT AND TRAINING

Recommendation 17 – Dyslexia-friendly workplaces

A national program should be established for the development of ‘dyslexia-friendly’ workplaces detailing specific inclusion (at all levels of policy and practice) of the needs of employees who have dyslexia. Employment seekers with dyslexia should be eligible for funding under the Workplace Modification Scheme (this provides funding to people with disabilities to modify the workplace - physical modification, or the supply of assistive technology).

Recommendation 18 – Improving adult literacy courses

- The effectiveness of TAFE and adult learners programs in the remediation of adult illiteracy and access to learning / training should be evaluated.
- The Certificate I in Foundation Skills for Adults with Dyslexia course currently run at TAFEs in Western Australia should be adopted in all states and territories.
- Centrelink recommended literacy training courses should be monitored for effectiveness and accredited by specialists in the area of literacy difficulties.

DYSLEXIA RESEARCH FUNDING

Recommendation 19 – Funding for efficacy research

Funding for research to determine effective dyslexia support in schools, for example, funding for:

- Large randomised controlled trials of school-based dyslexia intervention studies including:
- Evaluation of the efficacy of dyslexia treatment programs
- Development and trial of models of dyslexia resilience programs and environments
- Development and trial of models of teacher training and whole school support for effective use of assistive technology by students who have dyslexia

The UK House of Commons Science and Technology Committee in its report dated 18 December 2009 recommended that “the Government . . . commission a large randomised controlled trial to identify the most effective and cost-effective early literacy intervention”.

A CONCLUDING EXAMPLE

One of the members of our Working Party, Jim Bond, has suffered throughout his life from profound dyslexia. Very recently he has begun to work with the Macquarie University Accessibility Services Unit. He is a man whose life has been transformed through the use of assistive technology. He has told the rest of us about the profound differences to his life that have resulted from his being able to access printed information independently for the first time in his life. In the space of a few weeks he has already begun a degree in political science at university, has been able to read the web (and its many references to himself), and his wife has had the first break in 30 years of having to read absolutely everything to him. Many other Australians need and deserve to have such opportunities made available to them.

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