

# **Pathways 6 Conference 2002**

## **Assessment and Classification of Support Needs**

**Trevor R. Parmenter & Vivienne C. Riches**

Centre for Developmental Disability Studies, Sydney University

*Keywords:* support needs, disability, classification

### **ABSTRACT**

Assessing and classifying the support needs of people who have disabilities is a critical issue, as appropriate, effective and efficient resource allocation is contingent upon correct assessment and classification. The Centre for Developmental Disability Studies (CDDS) has been undertaking research and development activities in this area for several years, investigating both process and instrumentation issues and identifying a profile of the support resources, functions and intensities required in key environments. These are based on environmental factors and individual preferences for support. CDDS has now joined with the University of Sydney and other industry partners in a collaborative project funded by an Australian Research Council Linkage Project grant (2002-2004). The aim is to develop a rigorous and robust support needs classification system that has a high level of acceptance by stakeholders in the Australian context, that captures current and changing intensities and types of support needed by people with disabilities during life transitions. The classification system articulates with the ICF and AAMR conceptualisation of disability, and is designed to permit equitable, effective and efficient resource allocation and therefore improve the quality of life of people with disabilities. The theoretical and conceptual basis for this system will be presented along with significant achievements to date and future applications.

### **1. INTRODUCTION**

There has been significant movement for change away from a service system premised on diagnostic classifications or an aetiological conceptualisation of disability to an ecological approach in recent times. This reflects the need for a better system to assess the support needs of people with a wide range of disabilities and to translate those needs into responsive and individualised service delivery (e.g. Schalock, 1999).

Classification systems are important as they serve a number of key functions: as statistical tools for the collection and recording of data; as research tools for the measurement of outcomes, quality of life or environmental factors; as clinical tools used in needs assessment, treatment and outcome evaluation; as social policy planning tools; and as educational tools for curriculum design and social application (WHO, 2001). Thus they serve to provide a common language and framework for the coding of a wide variety of information.

Historically, people with disabilities were defined and classified according to their diagnosis or type of disability, such as mental retardation or intellectual disability, cerebral palsy, psychiatric disability etc. This diagnostic or aetiological framework is currently reflected in both the World Health Organisation (2001) *International Classification of Diseases, Tenth Revision (ICD-10)* that provides a "diagnosis" of diseases, disorders or other health conditions

and in the American Psychiatric Association (1995) *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*.

Eligibility for service provision is often determined by such disability definition and classification systems, but unfortunately, significant gaps and overlaps in service provision commonly occur. Many people with disabilities feel they are made to fit available programs, and service provision is often fragmented with different disciplines and different agencies working more or less in parallel. This arrangement exists despite mounting empirical evidence demonstrating that teamwork, or *coordinated service provision*, is the most efficient and effective form of intervention (Wade & de Jong, 2000). In other words, resources should be distributed based on what a person with disabilities needs rather than on what professionals or agencies choose to provide.

In contrast, the ecological approach depends on evaluation of the discrepancy between a person's capabilities and skills and the adaptive skills and competencies required to function in an environment. It stresses the power of person-environmental interactions and the reduction of limitations and barriers to functioning and activity through the use of person centred support strategies (American Association on Mental Retardation {AAMR}, 2002).

The current conceptual and practical interest in the use of supports now extends across disability groupings, disciplines and rehabilitation areas, and includes education, vocational training and employment, families, community living, and health. Indeed, Australian service agencies are increasingly using the concept of 'support needs' in an attempt to effectively and efficiently allocate scarce resources to the rapidly increasing proportion of the population with a disability (AIHW, 1997).

## **2. SUPPORTS MODEL**

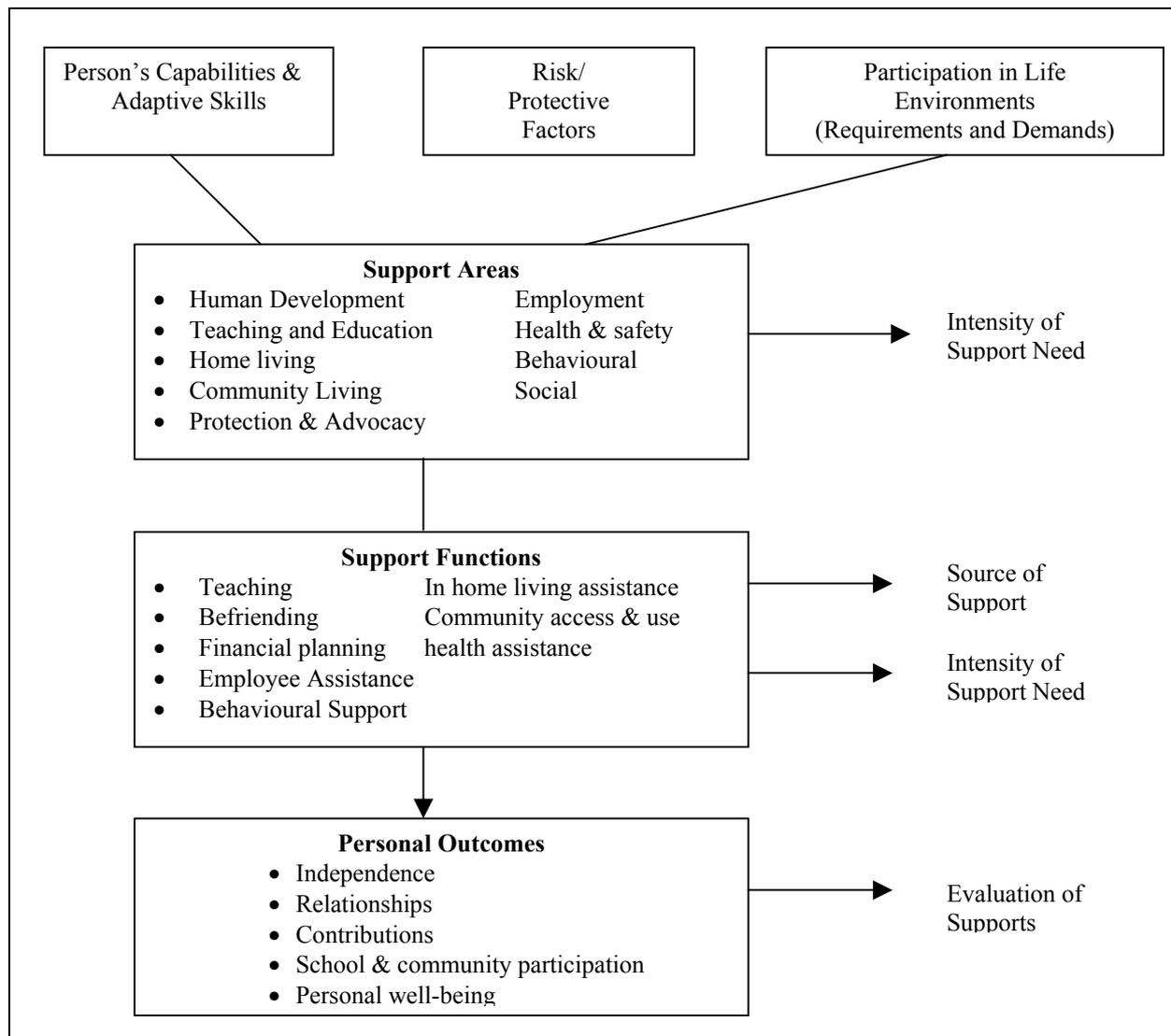
A paradigm shift occurred when the American Association on Mental Retardation {AAMR}, (1992, 2002) first adopted the concept of supports in its 1992 definition and classification of persons with an intellectual disability. The revised definition of mental retardation retained its requirements of a) an intelligence quotient ceiling of IQ 70, b) co-existing related limitations in adaptive skill areas and c) that the disability was manifest before the age of 18 years. Controversially, however, the supports model was based on the premise that appropriate and judicious use of supports can reduce the mismatch between environmental demands and a person's capabilities (AAMR, 1992; 2002; Luckasson & Reeve, 2001; Luckasson, Schalock, Snell, & Spitalnik, 1996; Schalock, 1995). Supports were defined (AAMR, 2002, p. 151) as:

*Resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning.*

The AAMR (2002) identified that supports (a) pertain to resources and strategies; (b) enable persons to access resources, information, and relationships within integrated school, work, and community living environments; (c) result in increased integration and enhanced personal growth and development; and (d) can be evaluated in reference to their outcomes.

The supports model (Figure 1) directly links support sources (natural or service-based) with the functions of support. Typically these functions involve receiving assistance with instruction, and/or friendship, finances, vocational training and employment, behaviour, home living, community access and use, and health. Assistance in these areas can take various forms, including supervision or monitoring; encouragement and reassurance, advice,

assistance to identify a range of options and issues to consider when choosing options; direct physical assistance; or the provision of instruction or training for the development of new skills or competencies. Across these various support functions, differing intensities of support may be required in terms of time duration, time frequency and power, concentration or intrusiveness. Consequently, some supports may be required only occasionally (intermittent); others may be time or occasion specific (limited); needed over an extended period (extensive) or of a frequent and intensive nature (pervasive).



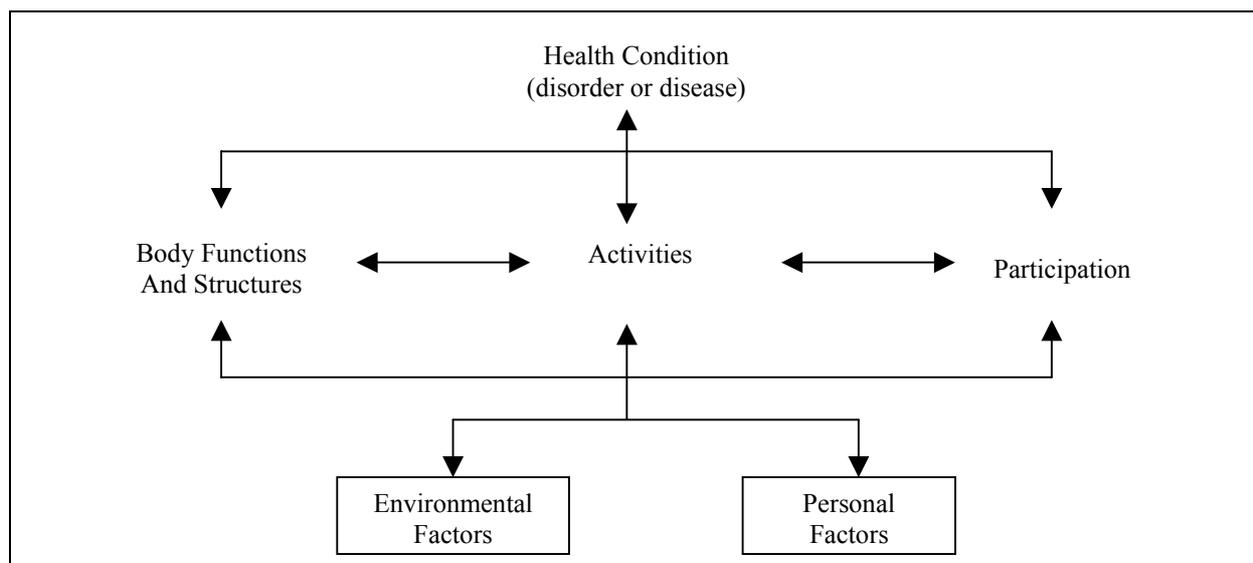
**Figure 1: Supports model for people with mental retardation**

The supports model is based upon a “best fit” assumption. That is, that a match between the supports needed and the type and intensity of the support provided results in desired outcomes such as achieving personal goals in key life areas. This requires a 3 step assessment process involving: (a) identification of relevant support areas, (b) identification of relevant support activities for each support area, and (c) determination of the level of support needs in each relevant support activity. For a student entering the post compulsory education and training arena, a number of specific support activities may be identified with regard to participating in training and educational decisions, learning and using problem solving strategies, operating technology etc. Additionally supports may be required in other key areas such as transport, social activities, self advocacy and empowerment.

Adoption of the supports model has far reaching consequences for all persons with disabilities. Disability can no longer be viewed as an absolute trait expressed solely by the person, but as an expression of the functional impact of the interaction between the person regardless of the level of intellectual and adaptive skills and that person's environment (Baumeister, 1987; Bruininks, Thurlow & Gilman, 1987; Greenspan & Granfield, 1992; Klein, 1992; Luckasson, Schalock, Snell, & Spitalnik, 1996; Schalock, Stark, Snell, Coulter, et al, 1994).

### 3. CONTEXTUAL FACTORS

Similarly, the recent determination by the World Health Organization (WHO) (2001), *International Classification of Functioning, Disability and Health (ICF)*, recognised disability as a dynamic state of restricted function affected by: (i) the interaction of the person (their health condition including impairment); (ii) the activities they desire to do (and any difficulties they may have in carrying these out); and, (iii) environmental and personal factors (restrictions on participating in the community such as physical access, discriminatory attitudes, particular background of an individual's life and living). This *bio-psycho-social* model (Figure 2) recognises that an individual's functioning in everyday life is the result of a complex relationship between these three components, and thus a person's *participation* in activities such as post compulsory education and training is either facilitated or restricted by environmental or contextual factors.



**Figure 2: Interactions between the components of ICF (WHO, 2001, p. 26)**

The underlying principle is that accurate identification of support needs and support planning requires a team effort. The challenge is to ensure an equitable resource allocation to permit people with disabilities to pursue their personal goals and chosen life activities. This requires a rigorous and robust system capable of accurately determining the type and intensity of support needed while taking into account the components of this complex relationship.

### 4. POST-SECONDARY EDUCATION ARENA

Attempts to identify the supports in the post secondary arena have been fraught with difficulties and confusion. This is due to the fact that the terminology used to describe assistance in legal and practical contexts changes across the environments of secondary

education, post compulsory education and employment, and that there are marked differences in the type of assistance offered across these environments (Stodden, Jones, & Chang, 2002).

Stodden et al (2002) contest that during the secondary school years where services are mandatory, needs are assessed and 'services' are planned and provided to and for individuals with disabilities, who in many cases are passive observers of the system. It is the responsibility of the school to ensure individual education plans (IEP) are developed, coordinated and implemented. Apart from curriculum adaptations, services and special environments often include reduced class sizes, increased attention to students by teaching and support staff, and less demanding work schedules.

As youth with disabilities transition to post-school environments where individuals are responsible for identifying themselves, the focus changes from the provision of services to 'reasonable accommodations' and 'non discrimination', and the level of support available also decreases significantly. Such accommodations often include priority enrolment, orientation, exam modifications, communication assistance, transcription services, access to adaptive technology, provision of note takers, tutoring, lab and library assistance, counselling, advocacy, and housing assistance. In this environment, it is the student's responsibility to obtain the required educational assistance, manage and monitor their support provisions, and balance these with any related services and supports (such as transportation and health care) (Brinckerhoff, 1994; Izzo, Hertzfeld & Aaron, 2001; Stodden et al, 2002). However, many students make this transition without the skills necessary to identify their own support needs and link their needs with desired outcomes (Grigal, et al., 1997; National Centre for the Study of Postsecondary Educational Supports, 2000; Stodden et al, 2002).

While youth without disabilities increasingly learn self determination skills, it appears the very processes instigated to support students with disabilities often shields them from learning and applying these important skills. Indeed, it appears that to achieve post secondary success, youth with disabilities need to be aware of the implications their disability has on their ability to function in this new environment, and the kinds of services and supports they are entitled to. They also need to possess the advocacy skills required to procure that assistance (Brinckerhoff, 1994; Izzo, Hertzfeld & Aaron, 2001; Stodden & Dowrick, 1999; Stodden et al, 2002).

## **5. SUPPORT NEEDS CLASSIFICATION SYSTEM**

The traditional approach to determining support needs has been to assess adaptive behaviours and more recently to also include a measure of functional performance. The Centre for Developmental Disability Studies (CDDS) has been undertaking research and development activities in this area for several years, investigating both process and instrumentation issues and identifying a profile of the support resources, functions and intensities required in key environments, particularly residential or living environments. These are based on environmental factors and individual preferences for support, using a multi-dimensional approach. This seeks to determine supports across significant domains, including physical assistance, health, communication and social skills, adaptive behaviour, behaviour and risk.

In an initial study in a residential setting, the 5 domain scales and the risk profile enabled a comprehensive profile to be developed for individuals with intellectual disability, that summarised the level of support required. This provided an overall estimate or level of support that could be compared to others in the sample. Using regression analyses, the adaptive behaviour, communication and basic physical care domain scales were found to

predict a substantial amount of staff support hours required by each individual, particularly during the day time. The medical/health and behaviour domains and the risk profile information further informed the amount of support required, and accounted for some of the variation in night support requirements. Altogether, these domains predicted 58% of staff support hours over a 24 hour period. Some allocation of staff support hours was not explained by these measures, suggesting that some allocation of resources may be linked to administrative and other issues rather than individual need (Riches, Stancliffe, & Griffin, 2000).

CDDS has now joined with the University of Sydney and the Royal Rehabilitation Centre, Sydney (RRCS) in a collaborative project funded by an Australian Research Council Linkage Project grant 2002-2005. The aim is to develop an innovative, rigorous and robust system of identifying and classifying support needs based on the conceptual framework that has been promulgated by AAMR (2002) and WHO (2001). Specifically, the project will develop a comprehensive, multi-dimensional support needs assessment and classification system that will validly and reliably identify the support needs of people with diverse disabilities in a range of everyday situations, including further education and training.

Currently an investigation is under way exploring the utility, validity and reliability of the instrument in measuring supports across a range of disabilities and environments, using the domains of physical assistance, communication and social skills, adaptive behaviour, health, behaviour and risk. A further development will then be to develop additional domain scales specifically for education and training supports. Contributions and involvement is welcomed from students with disabilities, families and education and training providers.

The project also aims to identify significant changes and transitions in the lives of people with a disability and the potential impact of these on type and intensity of need for support. It will assess the practical utility of the system to all interested parties (the person with a disability, their family, carers and advocates and service providers) in reliably and validly identifying support and service needs. Particular attention will be paid in relation to a linked support planning process, which ensures efficient, effective and fair distribution of support services.

## **6. CONCLUSION**

There is a clear need for youth with disabilities to be adequately prepared to understand the nature of assistance provision and support as they transition from the secondary to the post compulsory education and training environment. Moreover, they require self advocacy, self awareness and self determination skills to become active participants in the process of obtaining the necessary natural and paid supports required to successfully negotiate and achieve their desired futures. It is hoped that the support needs classification system will provide a mechanism for further empowering students in this endeavour.

## **7. REFERENCES**

- American Association on Mental Retardation, (AAMR) 1992, *Mental Retardation: Definition, Classification and Systems of Supports*. 9th Edition. Washington DC: Author.
- American Association on Mental Retardation, (AAMR) 2002, *Mental Retardation: Definition, Classification and Systems of Supports*. 10th Edition. Washington DC: Author.

- American Psychiatric Association, 1995, *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition DSM-IV International Version*. Washington, DC: Author.
- Australian Institute of Health and Welfare (AIHW), 1997, *Demand for disability support services in Australia: size, cost and growth*. Canberra: Author.
- Baumeister, A.A., 1987, Mental retardation: Some conceptions and dilemmas. *American Psychologist*, 42, 796-800.
- Brinckerhoff, L.C., 1994, Developing effective self-advocacy skills in college-bound students with learning disabilities. *Intervention in School and Clinic*, 29(4), 229-237.
- Bruininks, R., Thurlow, M., & Gilman, C.J., 1987, Adaptive behaviour and mental retardation. *Journal of Special Education*, 21, 69-88.
- Greenspan, S., & Granfield, J.M., 1992, Reconsidering the construct of mental retardation: Implications of a model of social competence. *American Journal of Mental Retardation*, 96, 442-453.
- Grigal, M., Test, D., Beattie, J., & Wood, W., 1997, An evaluation of transition components of individualized education programs. *Exceptional Children*, 63(3), 357-372.
- Izzo, M.V., Hertzfeld, J.E., & Aaron, J.H., 2001, Raising the bar: Students self determination + good teaching = success. *Journal of Vocational Special Needs Educators*, 1-28.
- Klein, J. (1992). Get me the hell out of here: Supporting people with disabilities to live in their own homes. In J. Nisbet (Ed.), *Natural supports in school, at work, and in the community for people with severe disabilities*. Baltimore: Paul Brookes Publishing Co.
- Luckasson, R., & Reeve, A., 2001, Naming, defining, and classifying in mental retardation. *Mental Retardation*, 39 (1), 47-52.
- Luckasson, R., Schalock, R.L., Snell, M.E., & Spitalnik, D.M., 1996, The 1992 AAMR Definition and Preschool Children: Response from the Committee on Terminology and Classification. *Mental Retardation*, 34(4), 247-253.
- National Centre for the Study of Postsecondary Educational Supports, 2000 June, *National survey of educational support provision to students with disabilities in postsecondary education settings: Technical report*. Honolulu, HI: Author.
- Parmenter, T.R., Whaite, E.A., Stancliffe, R.J. & Atkinson, N. (1998). Supported living services for adults with high support needs: A model prepared for Careforce. Sydney: Centre for Developmental Disability Studies, University of Sydney.
- Riches, V.C., Stancliffe, R., & Griffin, T., 2000, *Support Needs Classification Instrument: Evaluation Report*. Sydney: Centre for Developmental Disability Studies.
- Schalock, R.L., 1995, The assessment of natural supports in community rehabilitation services. In O.C. Karan & S. Greenspan (Eds.), *Community rehabilitation for people with disabilities* (pp. 184-203). Newton, MA: Butterworth- Heinemann.

Schalock, R.L., 1999, A quest for quality: Achieving organizational outputs and personal outcomes. In J.F. Gardner & S. Nudler (Eds.), *Quality performance in human services*. Baltimore: Brookes.

Schalock, R.L., Stark, J.A., Snell, M.E, Coulter, D.L., Polloway, E.A., Luckasson, R., Reiss, S., & Spitalnick, D.M., 1994, The changing conception of mental retardation: Implications for the field. *Mental Retardation*, 33 (3), 181-93.

Stodden, R.A., & Dowrick, P.W., 1999, Postsecondary education and employment of adults with disabilities. *American Rehabilitation*, 25(3), 19-23..

Stodden, R.A., Jones, M.A., & Chang, K., 2002, Services, supports and accommodations for individuals with disabilities: An analysis across secondary education, post secondary education and employment. Unpublished paper. Centre for Disability Studies, University of Hawaii.

Wade, D.T., & de Jong, B. A., 2000, Recent advances in rehabilitation. *British Medical Journal*, 320, 1385-1388.

World Health Organization. (2001). The International Classification of Functioning, Disability and Health (ICF). Geneva: Author.

## **Curriculum Vitae**

### **PROFESSOR TREVOR R. PARMENTER, PHD, FACE, FAAMR, FFIASSID**

Trevor Parmenter holds the joint appointment of Foundation Professor of Developmental Disability in the Faculty of Medicine at the University of Sydney and Director of the Centre for Developmental Disability Studies (CDDS). He also holds the appointment of Adjunct Professor in the Faculty of Education at the University of Sydney and Visiting Professor at Macquarie University. Prior to his appointment at CDDS in 1997, Professor Parmenter held the position of Professorial Fellow in the School of Education, Macquarie University and Director of the Unit for Community Integration Studies. Previous to his appointment to Macquarie University in 1974, he held teaching and administrative positions with the NSW Department of Education (1953-1973). Areas of research expertise include: Research into behavioural and emotional problems of people with disabilities; Quality of life assessment; Program evaluation; Community living and employment for people with disabilities; Assessment of cognitive processes; Brain injury; Family studies; Transition from school to further study, work and adult living

### **DRVIVIENNE CATHERINE RICHES, BA, DIP.ED, MA (HONS), PHD, MAPS**

Vivienne Riches is a registered psychologist and senior research fellow, Centre for Developmental Disability Studies and Sydney University and conjointly holds positions as clinical senior lecturer, University of Sydney, and clinical psychologist, Royal Rehabilitation Centre, Sydney. Dr Riches has extensive experience in teaching and training, quantitative and qualitative research, program and policy development, assessment and classification, curriculum development, individual program planning, program intervention, and clinical practice.

## **CONTACT DETAILS:**

Centre for Developmental Disability Studies

PO BOX 6 RYDE, NSW 1680

Telephone 02 8878 0500

Fax 02 98077053

Email: [trevorp@med.usyd.edu.au](mailto:trevorp@med.usyd.edu.au)

[vriches@med.usyd.edu.au](mailto:vriches@med.usyd.edu.au)