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The Role of the Clinical Specialist in the Disability Service System

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Introduction

The disability service system is a complex ecology which needs to be understood as part of a wider ecosystem that is our society. It is primarily comprised of people, with and without disability, and is made manifest in social, economic and political discourse. It is both a product and a reflection of our wider society and, at the same time, it can be an agent of change in our community. Its existence can be explained and justified as both a mechanism to support people with disability, and as a means by which society expresses its self and its relationship with those members of the community deemed to be ‘the disabled’. The disability service system is therefore much more than simply a network of service options for a particular group of people. Any future reform agenda needs to acknowledge and reflect these complexities, as will the specialist staff deployed in the service of people with disability in our community.

In addressing the theme of this 2010 LaTrobe Annual Round Table on Intellectual Disability Policy, “Victorian disability policy for the next 10 years – what should it look like?”, this paper will address the potential role of the clinical specialist in the complex ecology of the disability service system of the next decade, and pose questions such as, ‘is there a role for the clinical specialist’, ‘are clinical specialist more than simply a service option within a broader service system’, and how might this role be best conceptualised and deployed to the benefit of people with disability, family carers, service providers and the wider community?

This paper will not attempt to address the question of ‘do we in fact need a specialist disability service system’, or if elements of what is offered by the specialist disability service system might be more appropriately (and effectively) sourced from other service systems in our community; this is a whole other debate, and one which is worth having. This paper however, will first review our understanding of people with disability and the agenda which has already been set in the form of the disability service system we currently know. It will then explore the notion of the clinical specialist, and how this role has traditionally been used in the service system. It will review several models of practice that could inform and shape the role of the clinical specialist. The paper will conclude by presenting some practical examples of practice models that potentially point the way forward for the clinical specialist in the disability service system of the next decade.

People with Disability as Defined by the Service System

Those persons identified as ‘the disabled’ in our society, and in receipt of disability services, have been referred to and defined in a variety of ways. Traditionally, these definitions have identified ‘the other’, whose personhood is described in terms of its deviation (deviance) from that which is considered to be the norm for the wider society (Goggin & Newell, 2005). The emphasis has been on a deficit model of understanding disability. This deficit model is affirmed in each of the major texts which define disability, and intellectual disability in particular, and which have informed the development of the disability service system and the practice of clinical specialists within that system. Table 1 provides an overview of each of the three contemporary definitions of intellectual disability commonly referred to in clinical practice, and influencing the role of clinical specialists.

The deficit model of disability is evident in our Disability Act (Victoria) of 2006. The Act (Section 3) defines those members of our community who are entitled to access the disability service system as being persons with:

(a) a sensory, physical or neurological impairment or acquired brain injury or any combination thereof, which (i) is, or is likely to be, permanent; and (ii) causes a substantially reduced capacity in at least one of the areas of self-care, self-management, mobility or communication; and (iii) requires significant ongoing or long term episodic support; and (iv) is not related to ageing; or (b) an intellectual disability; or (c) a developmental delay.

The very fact that we refer to our specialist staff in the disability service system as clinical itself arises from, and serves to perpetuate a deficit model of disability. The term is borrowed directly from the medical model of disability, with the implication being that specialist staff and services are provided to address or remediate clinical issues; those arising from a state of illness. Furthermore, the term clinical in reference to specialist staff also has implications for how those staff might perceive the manner in which they are to work; i.e., clinically – focusing on the objective observation and treatment of disease and working in a detached and emotionless way (cf. Macquarie Dictionary, 2010).

While the objectivity and detachment of staff are arguably important dimensions of professionalism
to be maintained, much of our work in human services generally, and disability services in particular, is predicated on the quality of the relationships that develop between client and service provider. For these reasons, the traditional professional model which separates the client and practitioner (for a lot of very defensible ethical reasons) might not be the best model for disability services, and benefit from reappraisal.

In seeking to define a contemporary role for clinical specialists in disability services, their relationship with the people they serve is an area which requires ethical reflection, public debate, systematic research and policy development. With respect to the relationships that can emerge, or indeed might be necessary in the provision of effective professional services for people with disability, their family carers and service providers, we need to ask how far are we prepared to go in exploring and developing effective relationships and how far do we in fact need to go?

It might be that before we can define the role of the clinical specialist, we first need to develop a more sophisticated understanding of people with disability and the relationships that exist between people with disability and those who serve them. Undoubtedly this relationship will be one which is far more complex than the current conceptualisation of a simple dichotomous ‘client – professional’ relationship. Here I would argue that it is only after we have come to better understand people and their relationships that we can start to define roles.

### Clinical Specialists and their Role as Defined by the Service System

If in recognising the complexity of the issues presented by members of our community identified as ‘having a disability’ or ‘being disabled’ we provide specialist staff, should these staff be limited to those from the traditional clinical disciplines (and in so doing, continue

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**Table 1.**

People with disability defined in the major classification systems.

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| **Diagnostic criteria must meet:**  
A. Significant sub-average intellectual functioning; an IQ of approximately 70 or below on an individually administered IQ test.  
B. Concurrent deficits or impairments in present adaptive functioning (i.e. the person’s effectiveness in meeting the standards expected for his or her age by his or her cultural group in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.  
C. The onset is before age 18 years. | A condition of arrested or incomplete development of the mind, characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition.  
Degrees of mental retardation are conventionally estimated by standardized intelligence tests. These can be supplemented by scales assessing social adaptation in a given environment.  
Intellectual abilities and social adaptation may change over time, and, however poor, may improve as a result of training and rehabilitation.  
Diagnosis should be based on the current levels of functioning. | Significant limitations in intellectual functioning and adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.  
The following five assumptions are:  
1. Limitations in present functioning must be considered within the context of community environments typical of the individual individual’s age peers and culture.  
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioural factors.  
3. Within an individual, limitations often coexist with strengths.  
4. An important purpose of describing limitations is to develop a profile of needed supports.  
5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve. |
to emphasise that disability service provision is primarily about addressing deficits), or should our specialist service provision be seen in a much broader context? And if so, who might provide such specialist services, and how might these specialist disability services interact with and complement generic community services? For example, if the issues of the day are about community presence and participation, are these issues most appropriately addressed by a psychologist, speech pathologist, occupational therapist, physiotherapist, nurse or a social worker? Arguably, all could contribute to the development of a comprehensive support programme, depending upon the person's individual needs and priorities, and where the barriers to achieving their goals are conceptualised in terms of deficits inherent in the individual attributed to their disability. Or are there others with specialist knowledge and skills who might be better positioned to provide the analysis, advice and the support needed, especially where the barriers reside in the social and political structures of our community? The title of clinical specialist aside, the perpetuated emphasis on the deficit model of disability has set the traditional 'first item on the agenda' for our clinical specialists; that of assessing, defining and measuring deviance. However, here it must be stressed that assessment itself is not a bad thing; and is arguably an important role of the clinical specialist that should not be abandoned, but rather strengthened and enriched. If an assessment brings about access to a much needed service and, as a consequence of a thorough assessment, that service can then be delivered in a targeted and effective manner consistent with the person's identified needs, then it could be argued, on the basis of teleological ethics, that the ends justify the means. That is, thorough assessment, inclusive of the identification of deficit, is an important role for the clinical specialist in disability services. Here though what is obvious, but all too often breached in practice, is that the assessment by the clinical specialist needs to go beyond defining deficit, to the identification of strengths.

However, even more important than the identification of strengths, consistent with the person-centred agenda, our clinical specialists need to operate in a policy environment and, importantly, to have a skill set, that enables them to go beyond the assessment and measurement of mere deficit and strength in domains of, for example, intelligence, adaptive behaviour, communication, mobility and health, etc. They need to be able to work within an evidence-based assessment framework that enables them to identify human and systemic potentials, and goes even further to objectively and faithfully document the aspirations of those they are assessing. They then need to be able to both provide advice and guidance on how these aspirations might be realised, and be prepared to work with the person to together discover how such aspirations might be realised (in ways never before conceptualised by the specialist clinician). Here we see a role for the clinical specialist emerging that is far more than an embodiment of expertise, but rather a partner and travelling companion on a journey of discovery. Consequently, we need to ask the question, how well are our existing clinical specialists prepared for this role, and how might disability policy establish an environment to support them in such a role?

Again, we need to revisit the traditional notion of the clinical specialist within the disability serviced system. If our service provision relies on clinical specialists, then the lens though which assessments are to be conducted will by default be clinical in nature, and primarily focus on and emphasise clinical issues (e.g., behaviour support, communication difficulties, physical or mental health problems). If however, the critical issues are wider than those defined in a traditional clinical context, then we need to plan for and develop a service system that can harness a broader range of specialist knowledge, skills and expertise.

While acknowledging the specific focus of the lens of our clinical specialists, our clinical specialists still have a vital role to play in moving us as a service system and a society beyond a deficit focused disability agenda to service system that recognises:

Disability is not simply a quality or attribute inherent in an individual person that requires treatment or cure. Rather disability comes about as a consequence of the complex interaction between biological, psychological and social factors, including physical, economic and attitudinal barriers to participation at home, in education, at work, or in the community generally (McVilly & Newell, 2007; pp. 10-11).

To these ends, a possible framework to inform the emerging role of the clinical specialist in the disability service system, together with the policies and procedures associated with that role (and by implication any future state disability policy), is that offered by the World Health Organisation's (2000) International Classification of Functioning Disability & Health [ICF]. The ICF framework for understanding human functioning stands alongside, compliments and counterbalances the deficit focused diagnostic system of the World Health Organisation's (2007) International Classification of Disease [ICD-10]. The ICF offers a lens though which to look at human functioning...
and plan for an agenda of enablement, rather than cure or palliation. The ICF framework challenges clinicians and the wider service system to adopt a bio-psycho-social model to our understanding of all people (not just those labelled as ‘the disabled’).

The ICF framework deconstructs (while maintaining an emphasis on the interrelatedness of) consideration of a person’s body structures and functions, their activities and participation in society, and the contextual factors, both in the environment and for them personally, which mediate their life experience. A strong theme underpinning implementation of the ICF framework is the identification of what it means to be a healthful human person (remembering that ‘health’ is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity; WHO, 1946), to identify human potential, the barriers to those potentials, and what is required to maximise quality of life. Also, importantly, the ICF framework provides a common language for clinicians and other specialist service providers as well for researchers and policy makers; to allow for and promote multi-disciplinary, inter-disciplinary and trans-disciplinary practice (to be discussed below). Application of the ICF framework to the state disability policy would by necessity require clinical practitioners and policy makers to have a thorough grounding in biological, psychological and sociological issues which contribute to, perpetuate and at times enhance the individual’s experience of disablement, but which can also be harnessed to redress and habilitate that experience.

Consistent with the bio-psycho-social model of the ICF, in addition to the exercise of their focused (clinical) expertise, the role of specialist staff in the disability service system needs to encompass the active and intentional promotion of quality of life and personal wellbeing. The scope of this paper does not allow for a comprehensive overview of all that might encompass the promotion of a quality life. However, suffice to say the key issues of consideration for people with disability have long been established as those same issues effecting the lives of people in the general population, and include such factors as: relationships, financial security, health, education, opportunity for meaningful activity, personal safety, and future prospects (for reviews see McVilly & Rawlinson, 1998; and Schalock et al. 2000).

But how might any one clinician grasp such a breadth of practice? Is this all-encompassing role realistic for any one practitioner? The answer is no! This brings us to a consideration of not only the role of the specialist clinician in the disability service system, but also the modus operandi of such specialists and different ways of organising such services.

Different Ways of Organising and Resourcing the Provision of Specialist Clinical Services

Given the complexity of people’s circumstances and support needs, it is evident that reliance on the traditional sole practitioner / consultant will be insufficient to sustain a comprehensive disability service system of the 21st Century. What then of the much touted multi-disciplinary team?

Multi-disciplinary teams have in the past been one response of the disability service system, in an attempt to organise their specialist clinicians in a way that recognises the multiplicity of expertise that is needed to support people with complex life situations. See figure 1. Such teams have often been modelled on the convergence of disciplines used in hospital settings to address ‘complex cases’. They have been most evident in paediatric assessment settings (especially in diagnostic centres for Autism Spectrum Disorder) and more recently in behaviour intervention services. However, such teams all too often limit their collaboration to the assessment process, and even then maintain well defined professional boundaries in their report writing and service provision. At best, the client’s progress might be monitored by means of a multi-disciplinary case conference process.

Figure 1. A Multidisciplinary Model

In an attempt to address the shortcomings of the multi-disciplinary team approach, the interdisciplinary mode of clinical practice has been developed (cf Choi & Pak, 2006). See figure 2. While going some way to integrate assessment and to prepare collaborative reports, support, intervention and treatment services have largely remained disjointed, with disparate programmes implemented in relative isolation from each other, delivered according to traditional discipline-specific protocols.

Here it is proposed that it is the transdisciplinary team approach which might offer a way forward;
for defining the role and shaping the practice of specialist clinicians in the disability service system of the future (cf Soskolne, 2000). See figure 3. Such teams are predicated on collaboration between experienced clinicians who have confidence in their own capacity to not only undertake their own core professional duties, but to also take on, within the bounds of their own professional competence, some of the tasks associated with other professions, and at the same time have sufficient confidence and trust in their colleagues to allow for role release where by their colleagues undertake some of the tasks that they would have traditionally performed. Of course this discussion must span a myriad of practical, professional, legal and ethical issues. Here though one major question that does arise is, how do we attract and retain practitioners with sufficient experience and competence to operate in this way? State disability policy will therefore need to address issues concerning recruitment and retention of specialist clinicians, noting the difficulties faced by all states and territories in the recruitment and retention of such specialist staff.

Figure 3. An Transdisciplinary Model

Transdisciplinary practice is not without controversy, and is the subject to much professional debate. Furthermore, there is a paucity of research to establish it efficacy. Some would in fact argue that it not be adopted as the sole or primary mode of service delivery, but rather as one mode of service delivery within a wider service delivery system (Patel, Pratt & Patel, 2008). See figure 4.

To progress consideration of a transdisciplinary team approach, and to ascertain its applicability to the disability service system of the future, we need research to help us define the core characteristics and operational parameters to guide a service model such as this. Importantly, we need dialogue between the traditional professions which have come to dominate our disability service system, and the health and community services sectors more broadly. We also need dialogue with the tertiary institutions charged with the education and initial formation of our specialist staff. Such dialogue could be orchestrated by means of state disability policy which not only addresses the direct provision of services but also issues concerning the education and formation of practitioners to resource the service system.

On a practical level, if we expect different professions to work together in practice, it might be important that they commence by being educated together. To this end, there are already some limited examples of common undergraduate courses in the education of some clinical specialists in Australia, and some specific courses addressing the practical and ethical issues associated with multidisciplinary team work and transdisciplinary practice. Here of course any consideration of the adoption of transdisciplinary practices will also require that our specialist staff are educated in the conduct of such practice, which might not come as a matter of simple common sense.

The proposition of transdisciplinary practice again raises the question of which disciplines are needed to best deliver effective specialist services in the disability sector, for people with disability, their families and those who support
them. What paucity of debate there currently is on this topic is predominantly one conducted among the traditional professions (e.g., psychology, medicine, nursing, social work, speech pathology, occupational therapy, physiotherapy). In preparing for future state disability policy, the involvement of a much broader group of professional stakeholders would enrich such a debate and the subsequent provision of specialist services.

When considering a broader understanding of who and what constitutes a clinical specialist in the disability service system of the future, we need also to explore the emerging role of the Direct Support Professional (in contrast to the current role of the relatively poorly trained Disability Support Worker), and the contribution these new and emerging professionals have to play in the arena of specialist service provision.

In the past, direct support was provided by professional staff – predominantly nurses. With the progress of deinstitutionalisation and a growing emphasis on community-based service provision, the role of staff who had been educated in traditional professional models of service provision, such as nursing, was gradually eroded with many of their functions assumed by relatively poorly trained ‘carers’. However, with a growing awareness that the support of people with disability can require a breadth of knowledge and an array of complex skills, there are moves internationally, and in Australia, for the re-professionalisation of the direct support workforce (McVilly, 2007). This too comes with controversy, including differing opinions on this topic among people with disability themselves. However, a more detailed discussion of these matters is beyond the scope of the current paper.

The emerging role of the direct support professional is an important element of the policy agenda that will by necessity influence our consideration of the role and scope of the clinical specialist in the disability service system. To what extent will these specialist staff work in a consultancy mode with Direct Support Professionals, and to what extent might they need to be available on a more regular basis to address the complexities of people’s every day needs, and to support the attainment of individually defined aspirations? It could be that the demands of a person-centred service agenda require greater availability of specialist staff who are better equipped to assess, interpret and to attend to individual needs, rather than relying on the more generic and process based skill set of the Direct Support Workers, who have in recent years been relied upon to provided more basic services. Subsequently, we could ask might there be a potential role in state disability policy for the recognition (and resourcing) of specialists in the form of well educated paraprofessionals, such as Social Trainers (as in Western Australia), Social Educators (as in New South Wales) or Social Pedagog (as in Germany and other European countries)?

Setting aside the question as to which classification of staff might rightly be recognised as specialists, it appears far more important to consider the key characteristics or attributes we expect practitioners in these roles to possess. One such characteristic that could be put forward for debate as to its relative importance in the formation and development of specialist practitioners in disability services, and the extent to which we want it exemplified in the practice of our specialist practitioners in the disability service system, is that of the scientist – practitioner (Raimy, 1950). This mode of practice is said to be characterised by three key features: scientist– practitioners strive to further understanding of their discipline through research, either within a traditional academic context, or through the examination and reporting of data obtained in their practice; they are a regular consumers of research, through which they improve their practice; and they are effective evaluators of their practices, programs, and interventions by application of the scientific method (Jones & Mehr, 2007). An important outcome to this mode of practice is the translation of research into practice. This is arguably one of the most important roles (and capabilities) we might expect of our clinical (and other) specialists in the disability service system; the ability to translate theory and research evidence into every day practice for the benefit of people with disability and those who provide their support.

If we are, like the wider community, to value science, the scientific method and the fruits of research, and science is to have a place in advancing the interests of people with disability, their families and those who support them, then we need our specialist staff trained in the scientist-practitioner mode of practice, and we need our service system more broadly to be equipped with the knowledge, skills, policies and procedures that can recognise and harness good science (and likewise recognise and reject bad science), and deliver the benefits of science to people with disability. To these ends, our state policies, procedures and practices all need to recognise that what is required is much more than simply a ‘common sense approach’, or indeed a ‘rights based approach’. We need to plan for a disability service system that is accorded the respect of ‘rocket science’. We need to plan for the provision of specialist practitioners with the knowledge and skills reflecting the ‘rocket science’ that is involved in the provision of complex human services for complex human beings.
Positive Behaviour Team would like to summarise three such examples: the are examples of good practice emerging. Briefly, I would like to summarise three such examples: the Positive Behaviour Team of the Western Australian Disability services Commission; the Marte Meo Team of the Department of Aged, Disability and Home Care in New South Wales; and the work of the Intensive Interaction Team, within the Victorian education system.

The Positive Behaviour Team (PBT) of the Western Australian Disability Services Commission was established as a pilot project to deliver behaviour support services to young people with disability living at home, and whose circumstances placed them at high risk of family breakdown and subsequently out of home placement. The team commenced with psychologists, speech pathologists and social workers. The discipline base is planned to be widened in the near future. All practitioners on the team are recognised as senior in their respective disciplines. They work in a transdisciplinary way, primarily in family homes, but also working in schools and day support services; wherever their clients spend time. While their brief certainly includes ‘behaviour change’, they measure success in terms of much broader issues, including parental coping ability and family quality of life. Their work is grounded in a range of meaningful interactions and activities designed to improve their well-being and quality of life.

The Marte Meo Team of the Department of Aged, Disability and Home Care in New South Wales has been established to deliver support services for people with disability both living with their family of origin and in supported accommodation. Members of the team come from a variety of disciplines. They have undertaken advanced accredited training in the Marte Meo technique, incorporating master classes and on-going professional supervision conducted by experts from the Netherlands. The technique involves predominantly video interaction feedback as the primary tool of practice. As with the PBT in WA, the Marte Meo Team’s practice is informed by an evidence base, and is subject to on-going monitoring and scientific evaluation. The modus operandi of the Marte Meo practitioners is to enable families and staff to discover the competencies of the people they support, and to discover and develop their existing competencies in the support they provide. An important by-product of the involvement of the Marte Meo Team is that at the end of their involvement, families and staff are not left with a bulky consultancy report but a rich resource of instructional video and, even more importantly, personal insight into how they can best provide support that enables the focus person to achieve according to person-centered goals developed during the Marte Meo process. Here we see clearly the role of the clinical specialist as an educator, not just a diagnostician or treatment provider.

The Intensive Interaction Team, within the Victorian education system provides direct support to students with profound intellectual and multiple disability (PIMD). The II team consists of a number of disciples working in close collaboration; including psychology, special education, speech pathology and occupational therapy. Their practice is grounded in an evidence-based curriculum developed in the UK over the past 25 years. The focus of their work is to discover how best to connect with an individual with PIMD, what that individual is interested in, and how that individual prefers to communicate. From there they begin to build a relationship with person that in turn supports the person to participate in a range of meaningful interactions and activities designed to improve their well-being and quality of life.

In the formation of each of these teams the value of education, experience and specialist knowledge is recognised, and high levels of professional skill and ethical conduct are expected. Traditional professional barriers have, to a large extent, been dropped in the conduct of assessment, the formulation of strategies and the delivery of services – but without compromising discipline specific knowledge and competencies, and in turn maintaining the highest standards of professional practice according to internationally accepted standards of accreditation. Person centred approaches characterise all aspects of their work, with practitioners adopting a stance that involves intensely listening to people, their story and aspirations, and from there harnessing their specialist knowledge and skills not for the diagnosis and treatment of deficit (though a thorough and professional understanding of factors limiting individuals’ opportunities remain important to supports planning), but to enable people to participate in their preferred sphere of life and to achieve their goals. Support services are delivered in close collaboration among practitioners within their respective teams, between agencies and, importantly, in close partnership with the people they serve, their families and others who support them.
These three service models offer some insight into the potential role to be played by clinical specialists in disability services. Importantly though, they also offer insight into the characteristics that constitute a contemporary approach to service provision in our field. They provide examples of some of the critical elements that need to guide policy and practice as we formulate disability policy for Victoria.

Conclusions
In future Victorian disability policy, there is a vital role to be played by clinical specialists. However, it will be a role that goes beyond the current practices and parameters of the traditional clinical disciplines. There will need to be new players at the table, greater respect for each other, and new ways of working together, including working with the new and emerging role of the Direct Support Professional. While maintaining expertise in identifying those factors that limit people in their daily lives, there will be a need to focus the role of our clinical specialists on translating research to policy and practice. Importantly, these specialists will need to implement and support policies and practices that build meaningful relationships, which enable people to have their rights and dignity respected, and to realise their aspirations as individuals and members of the wider community.

References


