A Consideration of "Community Response Programmes" for Disabilities or Other Issues of Common Concern

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The awareness of disability and diversity issues, and efforts to provide a more inclusive society with community-based services, have grown markedly in recent years. The university system, with mixed reactions, has grown more entrepreneurial - better able to cooperate with government and private agencies, and to respond to the community. The United States of America has a system of federally mandated programmes - University Affiliated Programs on Developmental Disabilities (UAPs) - that have evolved over the last 30 years in response to needs of people with disabilities. These programmes have successfully developed many of the cutting edge services, training, and research generally cited in support of best practices internationally: supported employment, full inclusion, self-determination, and applied behaviour analysis, to name some. This article provides a review of successful systems to support a model of "Community Response Program[me]s" that are university based, government mandated, and loosely but nationally organized. The focus, in the context of this Special Issue, is on disabilities - especially serious and persistent (chronic) disabilities. But the general concept of *Community Response Programmes* may be usefully applied to any area of common concern for which society has the will and the funding, and in which the university is willing to make the programmatic [academic] investment: juvenile crime, national identity, housing and homelessness, poverty, or peak performance.

There are worldwide differences in the way countries develop and provide support for people with serious and persistent disabilities. In the last 20 years, especially the last 10, I have observed and participated in a system in the USA currently known as "university affiliated programs." By any measure, these programmes have made large, valuable differences in the training, research, and systems of services affecting the lives of people with disabilities. At the same time, albeit from a distance, I have observed significant growth in the development of public and academic interest in Aotearoa New Zealand around issues of disability. The purpose of this article is to examine programmes that have been effective - more specifically, *systems* of programmes and their key features - to explore their consonance with ANZ developments.

UAPs in the USA

Much of the progress related to intellectual and physical disabilities in the USA has been stimulated, even fashioned, by federal legislation. In the 1950s, significant support was enacted through the Social Security Act for "Maternal and Child Health and Crippled Children's Programs." And the Kennedy family witnessed with dismay the inadequate and inappropriate treatment of one of their own - Rose, sister of John F. Kennedy. The greatest source of dismay, notwithstanding the brutality of electroconvulsive "therapies" and partial lobotomy applied to Ms. Kennedy, was the evidently aching gap between the services delivered in the institution and the knowledge base in the field. That awareness provided the impetus for singular legislation and remains important to this day.

President Kennedy appointed a distinguished Panel on Mental Retardation in 1961, as noted in a history of "University Affiliated Programs for Individuals with Developmental Disabilities" by Fifield and Fifield (1995). The panel's recommendations emphasized the need for training, and greater information and collaboration among agencies. The result was a federal act, signed into law by John Kennedy 3 weeks before his assassination, that established community mental health centers and regional "university affiliated facilities" (buildings attached to hospitals) for "mental retardation." Thirteen facilities were built and now over 70 programs with core federal funding can claim to be direct descendants of the original public law, P. L. 88-164 (1963).

Most US American law, applied to education, health, welfare and human services, is time limited - it includes what is known as a "sunset" clause. That is, the laws, regulations, and appropriations (fiscal support) lapse unless revised and renewed, typically every 3 or 4 years. The advantage, although hard earned and stressful for people in the field, is that support and emphasis is kept current. In this case, one major shift has been from mental retardation to "developmental disabilities," which does not include mild intellectual disability but does extend to serious physical (e.g., cerebral palsy) and sensory (e.g., blindness) and emotional impairments. Another major shift has been from "facilities" to "programs" - that is, not the buildings but the activities that go on within them, receive federal impetus and support. Hence the term is "university affiliated program" - UAP instead of UAF. Other changes include an emphasis on family issues, self-determination, and community-based services - indeed the full participation by individuals with disabilities in the community of their choice.

Many psychologists and others knowledgeable of disabilities and related areas are acquainted with "UAPs" although they may not be aware of their classification. Some notable members of the NZ psychological and educational professions have studied at such programmes. Likely-known programmes include the Child Health Bureau at the University of Kansas (associated with the Department of Human Development and the Center for Applied Behavior Analysis), the Kennedy-Krieger Institute at Johns Hopkins Medical School in Baltimore, the Nisonger Center in Columbus (Ohio), and the Child Development and Research Center at the University of Washington in Seattle. Recently invited specialists to NZ have included personnel from UAPs in New Hampshire and Michigan, and the American Association of UAPs. My own association has been with Alaska's Center for Human Development (as its founding director), Children's Seashore House at the University of Pennsylvania in Philadelphia, and now the Center on Disability Studies at University of Hawai'i - and visiting or affiliate appointments at other programmes, including the Child Health Bureau (U. Kansas) and the Kennedy-Krieger Institute (Johns Hopkins). As a member of the International Committee of the American Association of UAPs and the Asia Pacific Forum, I have taken a hard look at many long term programmes and new ventures to search out the elements that work in different circumstances. The aim is to identify some models or feaures that may be feasible in diverse national settings.

Developments in Aotearoa New Zealand

In recent years, a number of significant changes have been evident. These changes fall into three categories: (1) systemic innovations; (2) new organisations; (3) services levels and other activities.

Systemic innovations include legislated changes toward greater opportunities for people with disabilities to be included in society at large and the communities of their choice (Special Education Act, 1989). For example, the schools have a more active policy of including all children in regular schools and classrooms, rather than emphasizing segregated education (Thorburn, 1997). There is more acceptance in the community for people who are "different" (Sher, 1995). There is now supported employment in ANZ and it is increasingly an option for adults with disabilities (Bennie, 1995). There are increasingly outspoken and influential viewpoints from people with first hand experiences of disabilities, who are university professors, presidents of major advocacy organisations, etc. (Beatson, 1996; *Disability's Diplomat,* 1995; Munford, 1996; Sullivan, 1996; Theobald, 1996).

Among the new organisations, the *Journal of Disability Studies* seems a highly significant contribution. It was founded at Massey University Department of Sociology, whose efforts, particularly through two of its faculty (Peter Beatson and Martin Sullivan), have been notable in the field. The journal was recently taken over by the Donald Beasley Institute, another notable new organisation. In 1996, Auckland recently hosted the International Conference on Rehabilitation, a major event with scores of countries participating. Other organisations have come into existence primarily because of systems changes - Workbridge is a good example, an independent company providing services for adults with disabilities under contract with government agencies such as Specialist Education Services and the Accident

Compensation Commission. The steady production of applied scholarship has continued, including empirical intervention studies (e.g., Le Grice & Blampied, 1994) and significant reference works (Werry & Aman, 1993).

Thirdly, the levels of awareness and of services have increased considerably. Learning and using sign language is a real option for deaf people in ANZ, for example. It is still debated, but it has reached a level of acceptance and use such that new dictionaries of NZSL are available. ANZ has won a disproportionately large share of medals at Para Olympics and Special Olympics (*World Records Broken,* 1996). There are kneeling buses (gradually being introduced) and other accommodations. There are increasingly more wheelchair accessible street crossings, shops, offices, schools, restaurants, etc. than previously, although frustrating barriers still exist (M. Mathews & J. F. Smith, personal communication, September 1996).

National Programmes of Support for Disabilities

What can be achieved by way of services in any country is considerably determined by the national programmes - that is, the national agenda, legislation, and funding. Most countries have multiple levels of government (national/federal, state/provincial, county/municipal, etc.). Thus there may be multiple agendas, probably not in synergy. But for the purposes here, the simplifying assumption will be that there is a dominant, guiding authority that influences the development and delivery of services, and more indirectly the training and research, related to disabilities or diverse abilities.

Under a national agenda for the improvement of services to people with disabilities, the USA has mandated the existence of three types of programmes in every state. These are "planning councils," which continually assess the needs of consumers and ensure the awareness of government agencies, the "protection and advocacy" programme, which is legally prepared to act on behalf of consumers' rights, and the "university affiliated programs" (UAPs), whose main function is to provide training and otherwise develop services wherever necessary to meet the rightful needs.

These three (and other) programmes are defined and mandated in the congressional legislature (P.L. 103-230). The criteria for UAPs are spelled out in pages of detail. There are four main functions: interdisciplinary training, direct services, consultation, and dissemination. These relatively straightforward functional headings are further codified. For example, *inter*disciplinary is distinguished from *multi*disciplinary and *trans*disciplinary. The range of disciplines is described. Programs are expected to include psychology, (special) education, social work, and a health discipline such as medicine or nursing as cornerstones, and to build from there, or to justify alternatives. Training can be *pre*service, as in degree coursework, or *in*service, as in workshops, continuing education, or training of family members.

Direct services should be state-of-the-art, and will emphasize a community basis and family involvement. The UAP may choose not to deliver the services but to be the catalyst for upgrading or adding services in other agencies. Consultation can be to government agencies, community providers, families, or individuals. Playing a role in the development of legislation is a key function. Dissemination is broadly defined to include evaluative research, and can embrace the publication of flyers, videos, books, procedure manuals, scholarly articles, websites, etc. (see *Family Village,* 1998, for UAP websites and other information).

Integrity

The designation of "UAP," with associated, modest core funding, is usually assigned for 3 to 5 years, with some expectation of continuing indefinitely if specific criteria are met. Programs in general maintain their integrity through multiple sources of models, review, and consequences. Continuation applications are required annually, and re-applications are required at the end of each designation cycle. These (re)applications, naturally, involve an internal review of progress matched against previously stated objectives and published criteria. The criterion list includes 73 items (AAUAP, 1994). Examples include: "UAP's mission includes the active participation by individuals with developmental disabilities and their families," ". . senior professional staff hold appointments in appropriate academic departments . . ," "interdisciplinary training programs reflect state-of-the-art practices," "community training and technical assistance [consultation] is responsive to identified community needs," "dissemination products reflect the cultural diversity of the community."

There is also a periodic (3 to 5 yearly) external review process, conducted by peers from other national programs and consumers - and occasionally including representatives of the federal agency. Programs that do not meet criteria are not suddenly demoted but may receive a probationary period with specific goals to be met for continuation. In fact, positive models and instruction serve better than negative consequences. Thus there is a high level of communication among these programs, at least among the directors. There are regional meetings, a national association that

maintains a database, and active use of websites and other electronic communications.

At the same time, independence and innovation are valued. The university basis provides an academic freedom *modus operandi*. Programs tend to develop reputations for addressing certain issues (e.g., employment, transitions, community inclusion), which attracts personnel with those interests and increases the probability of additional project funding in those areas. Because of the history of their evolution, some UAPs have a medical emphasis, others are more oriented to special education or psychology. There is also room for individual influences by leadership personnel within the programs. Overall, the programs are very disparate in size, structure, and emphasis.

Mandate

The UAPs in the USA are mandated by congressional statutes, as noted above. The law sets out the general principles and some of the specific criteria for these programs. The language of the statutes has evolved over a period of more than 30 years with increasing amounts of input from the participants and advocacy groups.

The first generation emphasized facilities (usually children's hospitals) affiliated with universities to provide model services with training sites for a range of health-related personnel, including psychologists (Fifield & Fifield, 1995). The second generation emphasized other disciplines, particularly special education, and identified some focused initiatives such as early intervention, with an increasing recognition of the importance of community-based training and services. In the mid 1980s, the Congress mandated that "all states be served" under an expanding UAP system and the third generation put an even greater emphasis on community collaborations with specific target outcomes of "independence, integration, and productivity" (Federal Register, 1987). Recently, a fourth evolutionary phase is evident in which choice and self-determination - even greater participation by individuals and family members - are taking centre stage.

With the mandated existence of programs comes federal core funding. In the true sense of the word "core," this funding is US$200,000 per year. Most often this funding pays the salary of a director, some office staff, and for some stationery and paper clips, etc. Its purpose is to ensure the continuity of the basic program through the thick and thin of additional funding for specific good works. Typically, a program will secure, by competitive application, a few million dollars in funding per year for, say, a dozen individual projects ranging from 1 to 5 years duration. Some well established programs have secured additional predictable funding from the university or government sources that support some key activities, but are primarily for focused ventures such as post-graduate training or direct services requested by state agencies.

The arrangement of a "permanent" budget with self-determined spending at the heart of time-limited, project-specific funding has its advantages and disadvantages. The core provides stability and a basis of "leverage" - that is, the opportunity and the need to persuade other agencies *to align their goals with yours* and to pay you to help meet those goals. That provides considerable opportunity for a greater level of private enterprise or self-determined activity than is usual in university academic departments. But there are associated risks. The core is not enough to support faculty during the lean times. And very worthy plans for training, research, or development may not meet the priorities of funding agencies in timely ways to sustain viable staffing.

Quality

In summary, these entities called UAPs are *required to exist and to be accountable,* focused on a theme of developmental disabilities. Their existence and accountability are defined by clear criteria based on principles that offer the opportunity for flexibility and diversity - and constructive remediation, if necessary. How these programs differ from an interdisciplinary department may be explained in two descriptive phrases: *"cutting edge"* and *"responsive to the community."*

The programs are required to be *cutting edge* by wording in the legislation such as "state-of-the-art" and "exemplary." But that implies de-funding if criteria are not met, rather than ensuring the development and implementation of best practices in specific settings. Programs can foster the conditions that promote excellence by attracting and maintaining talented and dedicated personnel. These conditions are improved by seeking multiple sources of feedback and feedforward. The context of flexibility and self-determination improves creativity. And loss of recognition for non-achievement (rare in academic departments) is a consequence useful to keeping the mission headed in the right direction.

The implications for these features produce some predictable outcomes. Programs are interdisciplinary, not just to comply with stated criteria, but because serious and complex medical, educational, and community issues cannot be addressed in an exemplary way by a single discipline (Dowrick, 1994). Required self-evaluation keeps issues of excellence in the forefront. Additional external scrutiny is achieved

through the competitive process of grant reviews and publications. Programs have each other as potential models, and cutting edge training and services are put up for adoption and adaptation.

A program's *responsiveness to the community* can be assured to some extent by mandated outcome goals and sources of participation. It can be fostered further by the attitudes of its members and their receptiveness to the community - to the different ways that community issues may be expressed. Community activities need to be rewarded more than insularity. Programs can make an effort to attract personnel who place a high value on what they find rewarding in a community context. Positive and negative consequences to strengthen community responsiveness can accrue when government and private foundations emphasize these issues in their funding opportunities.

An implication of these arrangements is again the likelihood of interdisciplinary participation. But the most important outcome is *interagency collaboration,* a feature that is very striking in UAPs. The most successful of these collaborations include community members and are truly *inter*agency, not merely multiple agencies (cf. cooperative play vs. parallel play). Awarded grants tend to be applied and field based, rather than entirely initiated by the scientist.

These features of responsiveness are somewhat counterbalanced by the academic freedom provided by the university context and the fact that grants are announced as opportunities rather than compulsory. But it is the culture of *responsiveness* that transcends the birth and death of projects with individual, time-limited funding.

Relevance for Other Nations and Diverse Issues

The analysis above represents an effort to draw out features of UAPs that are effective. It presents no claim for a universal solution - in fact there is a tacit assumption that some of these programmes do not work nearly as well as others. It may look like a "single example" as it is indeed a single country. A more satisfactory analysis might be modelled on the treatise *In Search of Excellence* - featuring disparate companies than have successfully ridden the fortunes of time, not all located in the USA. But in fact, the UAP analysis is drawn from experiences with over 70 programs, albeit under just one legislative authority. These programs are very evidently disparate and variably effective across time and location (Davidson & Fifield, 1992). In Ireland, Romania, and Australia, national programmes have recently been implemented by local personnel, with invited support from USA UAPs. The features culled can be listed as follows:

- mandated through secure legislation
- supported through core funding
- answerable to clear and reasonable criteria
- provided with models, support, and consequences
- university based
- *cutting edge*
- *responsive to the community*
- designated with a theme (disabilities)

While there are many other identifiable features, such as interdisciplinary, collaborative, providing key activities (training, services, consultation, evaluation/ dissemination), I believe these features all result from those listed above and their natural content. My hope is that the listed features offer some universal characteristics that might enable the *adaptation,* rather than the adoption, of truly effective programmes that can make a difference to socially important issues in many countries - including Aotearoa New Zealand - should people in positions of influence so desire. The question of how effective will this paradigm be in other cultures and other systems of government, is a matter of application and empirical investigation.

The other question is, to what extent may the *community response program* model be applied to other issues of common concern? The programs in this review are all concerned with "developmental disabilities." But the summary above represents an effort to avoid features specific to the issues of developmental disabilities. Might not the model apply equally well to employment, multiculturalism, literacy, violence, teenage suicide, serious mental illness, homelessness, or poverty? Maybe it is significant that disability in the United States is more a human rights issue than a human services issue. (Several of the UAPs in the US call themselves "Centers for Community Inclusion" as if that represents their mission more than disabilities or human development.) Issues such as employment, delinquency, and homelessness are just as likely to fit the model, even so. So what about yachting, wine making, and political practice?

As a final note, I apologize for the "American model." Although I do not apologize for the United States as a country with much to offer in positive human endeavours and where I have had many unparalled professional and personal experiences, I am as conscious as anyone of the dangers of cultural imperialism. I despair at the ubiquitous news programmes, warehouse markets, fast food chain outlets, and their imitations (although the American influence in this country is still less than was the

British influence in previous decades). And I am also conscious of the trap in thinking that "foreign is (necessarily) better." I share with many readers a wish to stamp our public image and activities with Made in [A]NZ

But cultural imperialism is the bath water. We can keep a better baby, I believe, if we adapt rather than adopt. Thus the attempt here is to extract general features, with awareness of their context of origin. There appears to be much potential for the application in this country. Among several recent examples, the paper by Ratima, Durie, Allan, Morrison, Gillies, and Waldon (1996), which presents a model for culturally effective disability support to Maori, reads like a blueprint for any human services system - certainly one very resonant in US UAPs. So herewith is offered a challenge to Aotearoa New Zealand government agencies, the academics, providers, and consumers, to place Community Response Programmes in the local context and culture.

References

AAUAP Program Criteria Workgroup. (1994). *Program criteria for University Affiliated Programs.* Silver Spring, MD: American Association of University Afilliated Programs.

Beatson, P. (1996). Identifying ourselves. *New Zealand Journal of Disability Studies, 1,* 1-8.

Bennie, G. (Ed.). (1995). Supported employment in New Zealand. *Network,* Special Issue No. 2.

Davidson, P.W., & Fifield, M.G. (1992). Quality assurance and impact measurement of University Affiliated Programs. *Mental Retardation, 30,* 205-213.

Disability's Diplomat. (1995). *N.Z. Disabled,* December, p. 8.

Dowrick, P.W. (1994). So what's a "UAP," anyway? *Nursing Spectrum 30*(25), 12.

Family Village. (1998). http://www.familyvillage.wisc.edu/

Federal Register. (1987 November 20). *52*(224), pp. 44840-44850. US Government Printing Office: Washington, DC.

Fifield, M., & Fifield, B. (1995). *The evolution of University Affiliated Programs for individuals with developmental disabilities: Changing expectations and practices.* Washington, DC: Administration on Developmental Disabilities, US Department of Health and Human Services.

Le Grice, B., & Blampied, N.M. (1994). Training pupils with intellectual disability to operate educational technology using video prompting. *Education and Training in Mental Retardation and Developmental Disabilities, 29,* 321-330.

Munford, R. (1996). A position of marginalisation or inclusion? The experiences of women with disabilities. *New Zealand Journal of Disability Studies, 1,* 29-59.

Public Law 88-164. (1963). *Construction of university affiliated facilities for the mentally retarded.* US Congress: Washington, DC.

Public Law 103-230. (1994). *Devlopmental Disabilities Assistance and Bill of Rights Act Amendments.* US Congress: Washington, DC.

Ratima, M.M., Durie, M.H., Allan, G.R., Morrison, P.S., Gillies, & Waldon, J.A. (1996). A culturally effective framework for the delivery of disability support services to Maori. *New Zealand Journal of Disability Studies, 1,* 60-75.

Sher, B. (1995). What's new in New Zealand: Respecting individual differences in the community. *World Federation of Occupational Therapists, 31* (May), pp. 28-31.

Special Education Act. (1989). NZ Government Printing Office: Wellington.

Sullivan, M. (1996). Regulating the anomalous body in Aotearoa/ New Zealand. *New Zealand Journal of Disability Studies, 1,* 9-28.

Thorburn, J. (1997). *Including everyone: Teaching students with special needs in regular classrooms.* Christchurch: Allegro Press.

Werry, J.S., & Aman, M.G. (1993). *Practitioner's guide to psychoactive drugs for children and adolescents.* New York: Plenum.

World Records Broken. (1996). *N.Z. Disabled,* May, p. 7.

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