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Ownership of the Inclusion Agenda: Supporting Communities towards a more Equitable Education System.

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Abstract

Debates and policy initiatives aimed at the development of a more inclusive education system have provided an important focus for professionals from many disciplines in recent decades. At international level, initiatives such as the Salamanca Statement (UNESCO 1994), the Dakar Framework for Action (2000), and the Millennium Development Goals (United Nations 2000) have highlighted the shortcomings of previous generations of administrators and policy makers in providing adequate educational opportunities for learners who have been marginalised as a result of disability, poverty, gender or political upheaval. These laudable documents have encouraged national governments to initiate policies in an attempt to redress the balance and challenge the inequalities that have been pervasive in many education systems. The translation of policy into practice has however, often proven to be difficult and slow to take place. This paper considers the difficulties of addressing inclusion through a top down, policy led model and will discuss why such an approach may be experiencing difficulties in respect of implementation and impact. It is suggested that in order for inclusive education to succeed it is necessary to enfranchise local communities by building upon current local experiences and expertise which through implementing change at a local level may influence a broader national and international picture.

International influences on Inclusion

In recent decades evidence of an international commitment to provide education systems that are more equitable and just and that recognise the diversity of needs and abilities of individuals has increased. Governments from around the world have been keen to be seen to endorse international agreements such as those signed in Salamanca (United Nations Educational, Scientific and Cultural Organisation 1994) and Dakar (United Nations Educational Scientific and Cultural Organisation (2000) which have aimed to both raise awareness and engender national policy initiatives for the promotion of education for children who have previously been denied appropriate access to learning. The new millennium provided further opportunities for world leaders, supported by NGOs and professional bodies to highlight the challenges that remain in supporting the establishment of a right to education. The Millennium Development Goals (United Nations 2000) took a holistic view in relating educational targets to others aimed at the reduction of poverty, the improvement of maternal health and combating HIV/AIDS. This initiative should be applauded for its recognition that

a single focused approach to creating a more just society cannot be achieved through addressing issues such as education, poverty or the rights of women, but that rather a commitment to examining and tackling the relationships between each of these is necessary.

Quite rightly progress towards the Millennium development goals has been monitored with regular reports issued through the United Nations (see for example United Nations 2011). Conferences such as the IVth North South Global Dialogue in Goa have been used to assess those initiatives that have been promoted in support of inclusion as well as discussing obstacles to progress. Discussions of this nature are valuable, but those of us involved in these events and initiatives need to be clear about where our influence may have greatest effect and how we can ensure a co-ordinated response that moves beyond rhetoric and begins to support change in the communities where we work.

It is this theme of influence for change that provides the focus for this paper and it is the relationship between these undoubtedly important policy initiatives and the responses to them at grass roots level that I would like us to consider in our efforts to move forward. I will argue here that whilst policy at international, national and local levels is important in providing a framework for change and can encourage initiatives to improve the lives of groups and individuals, it is at the level of local initiatives that action leads to significant and sustainable change.

Building upon an ecological systems theory

In constructing an argument in favour of localised control and community based initiatives I refer to the work of Bronfenbrenner whose ecological systems theory (1979; 1995) interrogates the complex relationships between the many influences that impact upon individuals within society. Bronfenbrenner indicates that human development takes place within a complex environment which requires varying levels of interaction in order to progress. These complexities, within Bronfenbrenner's model inevitably impact upon the development of the individual child and the services that he and his family receives. However, they do so either through a process of direct

interaction between the child and his immediate environment, or less directly through the influences of structures, policies and legislation. The model below, based upon Bronfenbrenner's theories will be used throughout this paper to discuss the development of support systems for children and young people described as having special educational needs.

(Insert figure 1 here)

Policy initiatives: A tool for change or a means of appeasement?

The development and implementation of policy for the promotion of inclusion has been a feature of government legislation internationally. In response to the international initiatives highlighted at the beginning of this paper, many governments have put into place policies with the intention of supporting change in education and other caring services to enable increased and fairer access for children and young people with disabilities or from other marginalised groups. Examples of these policies from my own country would include the Special Educational Needs and Disability Act (SENDA) (Department for Education and Skills 2001a) and the Revised Special Education Code of Practice (Department for Education and Skills 2001b) which set out guidelines in relation to assessment and identification, multi-disciplinary support, and pupil and parent involvement in decision making processes. Similar legislation in the USA - The Individuals with Disabilities Education Act (IDEA) (United States Department of Education, 1990 revised 2004), Ireland – The Education for Persons with Special Educational Needs (EPSEN) Act (Oireachtas 2004) and India – Sarva Shiksha Abhiyan (Department of School Education and Literacy 2000) have endeavoured to recognise the need to create a more inclusive education environment and to ensure that learners whose needs have previously been overlooked receive schooling in a more equitable system. Similar examples of legislation could easily be cited from around the globe.

It is impossible to divorce the policy initiatives established by the governments of individual countries from those influential international initiatives introduced at the beginning of this paper. Indeed each of these international agreements are written in such a way that it would be difficult for

politicians to openly disagree with any of the sentiments expressed within them – universal primary education, increased access to schooling for marginalised groups, improved education for girls – without attracting the disapprobation of the international community. However, within Bronfennbrenner's model, international agreements such as the Salamanca Framework rest firmly within the macrosystem and at a considerable distance from the child and his family at the centre (microsystem) of the model. The influence of international agreements remains limited until such time as further actions are taken that might translate sentiment into statements of intent. This we have already seen has been instrumental in the passing of legislation leading to policies which sit within the exosystem of many countries, and we should not underestimate the importance of achieving this level of progress. It is only at a point where national policy is well defined and its intentions articulated that national systems of support can be developed. However, at this point there exists a series of challenges that vary from country to country and in some instances becomes an obstacle to progress.

Within the exosystem the implementation of policy is dependent upon cohesion between national and local governments and in some instances it is here that the adequacy of provision is most severely tested. In countries where there are good socio-economic conditions, well established welfare systems and political stability the communication of priorities between national and local government is more readily achieved. However, in other countries where there is disparity of wealth between states or regions, varying socio-economic priorities and a lack of social cohesion there is the potential for conflict in respect of policy implementation which may ultimately inhibit progress. Where this confusion within the exosystem happens we often see variations in the interpretation of policy which may become diluted or receive less priority than might be desirable. Where this occurs we often see disparate approaches to policy implementation in different regions of a country as those who are charged with the responsibility to manage the socio-economic wellbeing of the locality adopt different priorities. This ultimately means that the ability to support local communities and the facilities such as schools within them (the mesosystem) may become limited. Where this

happens the services provided to children and families within the microsystem is compromised, often leaving individuals frustrated and in some cases without the support they need.

This dilution of intentions emanates from a model in which power and control resides within the outer layers (macrosystem and exosystem) of the model and where the influence of those most directly affected by the challenges of disability or marginalisation are far removed from decision making processes. It is often the case that those who are most vulnerable within our societies have least influence in shaping policy and making decisions about how this might be implemented for the benefit of themselves and others (Penn 2005; Vickers 2009). Yet it may be argued that people with disabilities and their families have the lived experiences that are most central to ensuring that the decisions made on their behalf have the desired effect of ensuring a more inclusive provision. The slogan of "nothing about us without us" has particular resonance for families at the centre of systems that in attempting to provide a model of support from the outer circle inwards fail to achieve their objectives.

We can follow the logic of this argument most clearly by taking the specific example of an individual country. I have chosen India for this purpose but could just as readily have selected others. Representatives from India were in attendance at the World Conference on Special Needs Education: Access and Quality held in Salamanca Spain in June 1994 and were signatories to the subsequent statement that emphasised the need for increased inclusion and educational equity. Similarly, Indian officials have endorsed the Millennium Development Goals (2000) and have considered the means by which targets may be set towards their attainment (Ministry of Statistics and Programme Implementation, 2011). These agreements, which rest firmly within the macrosystem, along with others such as the Dakar Framework (2000) have clearly shaped national policy developments as is witnessed by the statements of intent within Sarva Shiksha Abhiyan (2000). However, partly as a result of the complexities within India we see that it is within the exosystem that disparities of policy emerge. Whilst the intentions of Sarva Shiksha Abhiyan and the

endorsement of a commitment to more inclusive education are clearly stated this has proven difficult to implement leading to an uneven development profile across the country. Examples of this are evident if we scrutinise the *Millennium Development Goals, Country Report* for India (Ministry of Statistics and Programme Implementation, 2011) which highlights considerable discrepancies in school attendance across states. For example for pupils aged 6 – 10 years (enrolled in classes I – V) it was reported that school attendance stood at 92% in Karnataka and 91% in Kerala and Maharashtra States, whilst in Bihar and Arunachal Pradesh the figures were reported as 72% and 75% respectively. Such differences are possibly to be expected when considering the many differing socio-economic conditions that prevail within the individual states of India, a country that has undoubtedly made significant strides towards providing improved education and welfare services in recent years, but continues to face challenges at all levels.

Inevitably, as a result of the challenges faced at the exosysytemic level it is possible to find considerable discrepancies when we examine schools and local community facilities within the mesosystem. As a result of this whilst some schools within the country have made significant advances towards providing a more inclusive education system (Unicef 2003) , others, as a result of poor resourcing, lack of teacher training and lack of local legislative direction are struggling in this area (Mehrotra, & Panchamukhi 2007).

The example given here from India could just as easily be replicated from several other countries. The systems adopted with an emphasis upon starting from the macrosystem in anticipation of benefiting the microsystem is problematic because of its reactive nature and I would propose that in order to overcome this we need to firstly consider adopting a more pro-active approach to facilitation of change.

(Insert figure 2 here)

In figure 2 (above) I present two alternative models for development. The first relates to that described as the current prevalent approach to attempting to develop inclusive schooling. It begins

with the macrosystem and exosystem of international agreements and national and local policy initiatives before arriving at a local community mesosystemic level for interpretation. At this point it is likely that the application of any actions taken to create a more equitable education system will be an approximation of that intended by policy makers in the earlier stages. It is equally likely that interpretation and actions taken will differ greatly across individual locations resulting in some families and children gaining good services whilst others are less fortunate. There is, however, an alternative approach which I here call the proactive model because it emanates from the positive actions taken at a local level as I will illustrate in two vignettes to follow.

In the proactive model initiatives are taken by those who are most familiar with the challenges that need to be addressed, in this case the families of children with disabilities. Such families often report isolation and the confusion that surrounds experiencing disability possibly for the first time. Alone these families remain insecure, however with organisation and through sharing their own experiences, needs and solutions with others they may be able to build strong networks of common interest and for mutual support. The actions that they can then take will retain a focus upon their needs and through a united approach is more likely to have an influence upon policy makers at the local level and even beyond. Because of their personal commitment, such activists are more likely to establish systems and processes that are sustainable and focused upon need.

This alternative approach to the reactive model is not without difficulties and I will return to these later in the paper. However, at the heart of the proactive model is a focus upon personal ownership and collective responsibility that I would suggest is more likely to bring about change controlled by the very individuals that national policies are intending, but often failing to support. In order to advance such an approach the commitment of individuals is paramount, but as we have seen throughout history, social change has often come from small beginnings initiated by well-motivated individuals.

A personalised motivation for change

The history of special and inclusive education is founded upon initiatives taken by individuals and groups of people based upon their personal needs and experiences. In my own country the early twentieth century saw developments based upon systems of patronage and benevolence often led by people of wealth or influence, which were important in fostering change for a population that had been marginalised within society (Segal 1974). However, well-meaning as many of these initiatives undoubtedly were, they were often based on an assumption that individuals with disabilities were in some way inadequate, dependent and not fit to take their place within society (Campbell & Oliver 1996; Stiker 1999). National legislation implemented throughout the first half of the twentieth century was founded upon medical deficiency models that made assumptions that individuals needed care and that this should preferably be administered at a distance from the rest of society. A process of biological determinism identified individuals on the basis of medical diagnosis used to categorize and label them in order that they could be managed and provided for by expert professionals who were perceived to understand their needs. This model of benevolence persists today and it was relatively late in the twentieth society that alternative social models of disability emerged and began to be accepted by professionals and policy makers and that the voices of individuals with disabilities began to be heard. The strengths and weaknesses of social models of disability have been debated elsewhere (Shakespeare 1996; Goodley 2001) and it is not within the remit of this paper to discuss these in detail here. However, it is important to note that without the emergence and organisation of groups of disabled individuals and their families, progress towards a more equitable education system could not be achieved.

In order to examine some of the progress that has been made in enabling children and young people to receive an education appropriate to their needs I intend to present two illustrative vignettes. These come from vastly differing countries but do I believe have useful parallels that may serve to illustrate why a grass roots movement for change is essential to the achievement of goals that may be inherent within wider national and international policies. Both of these examples, the first from

Iceland and the second from India demonstrate how the determination and motivations of individuals are important in starting a movement that with momentum gathers others in its wake and becomes a force for change. I will argue that the impact of these proactive movements is not to be measured in respect of their response to legislation, but rather as a catalyst for influencing policy itself.

Progression takes time but reaps rewards

Dóra Bjarnason is Professor of Sociology, Disability studies and Special Education at the University of Iceland where much of her research has explored the lives of people with disabilities and their relationships with professionals and the services that they provide. She is also the parent of a young disabled man who now leads a semi-independent life in Reykjavik the capital city of Iceland.

Iceland is a volcanic northern mid-Atlantic country with a population of around 330,000 people. It has a well-established welfare service. The majority of the population live either within the capital city Reykjavik (c120,000) or the Greater Reykjavik Area (c202,000).

In her book *School Inclusion in Iceland: The Cloak of Invisibility* (Bjarnason 2003) Bjarnason presents an account of her life with her son Benedikt as he grew from being a child to young adulthood. The story she presents is interesting not only as a personal narrative but also because of the reflection she provides on the challenges that both she and Benedikt faced from officials and professionals in several countries (in addition to her homeland Bjarnason has lived in several other countries, including UK, USA and Australia). Her personal experiences, coupled with a professional lifetime researching services has enabled her to provide a reflection upon the emergence of provision for people with disabilities and the roles of individuals in working towards their development. In her consideration of the evolution of services within an Icelandic context, Bjarnason provides a model that indicates the central roles played by both parents and professionals (Bjarnason 2010). She does so by examining a temporal model that began in the 1970's. During this period she states that there

were few facilities for children with disabilities and their families, who were usually regarded with sympathy or pity. Parents were often advised to institutionalise their children and to try for another , and hopefully perfect baby. However many, quite naturally chose not to accept this advice and began to initiate change through making contact with others in similar circumstances. They sought out other families with whom to unite in a search for support wherever possible, leading to Bjarnason describing them as "explorers". It was through the initiatives and persistence of these explorers that gradually facilities were provided on the basis of the demands which they made to people in positions of authority. The slow development of a critical mass led to the formation of pressure and support groups such as Styrktarfélag vangefinna and Örykjabandalagið which became prime sources of information for families as they campaigned for improved access to schooling for children with disabilities. With increased organisation Bjarnason suggests that these people became "pioneers" who navigated a path through the challenges of ignorance and bureaucracy in order to establish rights and effect change. As a result of their efforts schooling, albeit in segregated settings, was provided and the pressure that they brought to bear led to the recognition of a need to develop national policy. Throughout the 1980s these pioneers maintained their pressure for change and facilities and opportunities did improve. By the 1990s many services were in place and a new generation of parents, described by Bjarnason as "settlers" emerged. These parents were familiar with the available services, had good support networks around them and lived in an era where legislation had been passed specifically to facilitate greater access to schooling and other services.

Before discussing the strengths and possible shortcomings of this proactive, client led demand for change, I will present a second example which though similar in approach faced, and continues to confront significantly different challenges.

Adapt is an organisation that provides services, training and support for people with disabilities and their families and the professionals who work with them in India. Founded in 1972 by Dr Mithu Alur,

Adapt was formerly the Spastics Society of India and in parallel with those organisations founded in Iceland has built its foundations upon the drive and vision of committed individuals who at one time found themselves isolated or rejected as a result of ignorance about disability. Like Dóra Bjarnason, Mithu Alur is the parent of a young person with a disability, in her case a daughter. Also like Bjarnason, Alur lived outside of her country, in England at a formative time in her daughter's life. Indeed, she has written about the influence of living within a country with a well-established welfare and education service as significant in the initiative that she took to gather together other parents to form a network of support (Alur 2010). A pattern of activism built around educating other parents and combining forces to influence policy and change resulted in a strong combined voice that has helped to shape policy and give direction to professionals who have committed to working alongside Adapt as a well-respected organisation. In recent years The National Resource Centre for Inclusion in Mumbai, which was initiated through the offices of Adapt has attempted to bridge the gap between the macrosystem of policy and that of the microsystem of need and has formed important alliances between interested parties at all levels. The similarities of motivation and initiative between family activists in Iceland and India is clear. However, it is perhaps more informative to examine some of the significant differences that have had to be considered when moving towards similar objectives of equality and inclusion.

Unlike Iceland, India is a country with a population of almost 2,000,000,000 distributed around a vast and varied land mass. With 22 official languages (plus English) and many more dialects and providing a home to all the World's major religions, it is hard to imagine a country more diverse and contrasting with Iceland. Whilst Iceland has a well-developed welfare service, that provided in India varies considerably from state to state. Average life expectancy in Iceland is 78 for men and 83 for women as opposed to 65 for men and 67 for women in India.

These differences might lead us to expect that differing approaches to facilitating change would be needed in these contrasting countries, and this is certainly the case. Whilst in Iceland, with its more homogeneous and closely located population it was possible for Bjarnason's explorers and pioneers to organise themselves relatively quickly and to form a united voice for change. In India this has proven more challenging and has required Alur and her colleagues at Adapt to work with like-minded activists to establish regionally focused networks to address the languages and conditions of their own hinterland. Not surprisingly this has taken time, but the benefits that have accrued are to be seen in improved education and support services and emerging examples of inclusive practice that may become a model for other parts of India (Alur 2003).

Learning from the two examples

In both of the examples provided above the initiative for change has come from individuals who have formed networks with others in similar circumstances. The advantages of such an approach are many. Firstly, the drive for change is located in individuals and then groups who have a first-hand experience and understanding of the situations they want to change. Inevitably such groups are well motivated and with effective leadership they are able to articulate their feelings and needs to those in positions of influence and power. However, without the development of networks and organisation their own influence remains limited. It is only at a point where families who are at the microsystem of Bronfenbrenner's model recognise that they can begin to shape provision in their own communities and schools that they are able to move towards the outer circles of this model.

There can be little doubt that schools that have shifted towards a more inclusive approach have been as greatly influenced by the understanding and demands of families as they have by national policies and legislations. Similarly, in both Iceland and India it is possible to detect the ways in which well organised groups have shaped policy and brought about change at both state and national levels. However, whilst articulate and well educated parents have learned how to mobilise their resources and to take action in support of their children it is essential that they accept a

responsibility to advocate on behalf of those who are less well positioned to make their voices heard.

It would, of course, be naïve to believe that change is effected by pressure from the microsystem alone. As both Bjarnason (1996; 2002) and Alur (2009) have acknowledged establishing working partnerships with professionals who bring their own expertise and experiences to the table is critical if lasting change is to be achieved and sustainable systems put in place. It is equally dangerous to believe that one approach towards developing a more inclusive society can address the issues of every country. Whilst there are lessons to be learned from the similarities in the approaches adopted in India and Iceland, it is of essential that we acknowledge the differences of conditions, culture, confidence, approach and timescale that influence moves towards change. We are reminded by Borsay (2004) that how far one's impairment hampers one's ability in society is largely determined by the culture in which the disabled person lives.

Finally it is necessary to recognize a danger for those communities which reach the status of "settlers" as described by Bjarnason. Whilst progress has undoubtedly been made and in many instances resources and provision has improved there remains a worry that the settlers who find themselves in a position where support appears adequate and who have an image of the journey travelled thus far may rest on their laurels and that progress towards an ultimate goal of inclusion stalls.

In moving forward towards a more inclusive education system within a society that is built upon social justice and equality of opportunity, it will always be necessary to form partnerships and alliances. Throughout the twentieth century the ability to bring about change has been dependent upon policy developed at a distance from the very individuals it was intended to support. A

recognition of alternative approaches is required if the mistakes of the last century are not to be repeated.

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Figure 1

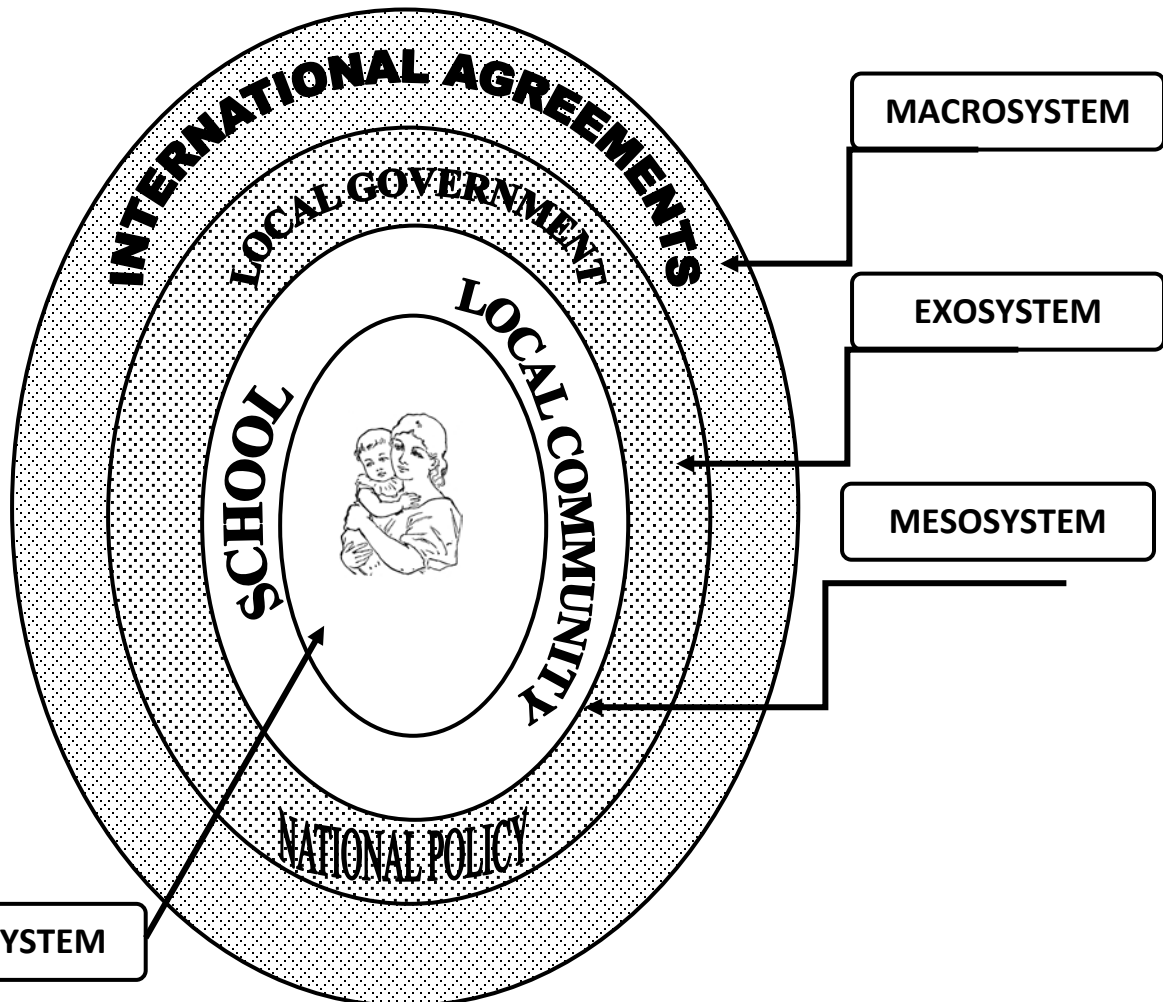Model developed from Bronfenbrenner's (1979) Ecological Systems Theory

Figure 2

Alternative Models of Development Action

Reactive Model	Proactive Model
International Recommendations	**Personal Understanding of Context**
National Interpretation	**Shared Experience and Understanding**
National Policy	**Action Focused on Need**
Local Interpretation	**Influence Based upon Experience and Critical Mass**
Approximated Action	**Extension of Influence through Organisation**
	Sustainable Policy Based Upon Ownership