

PARTNERS MATERIAL FOR WEEKEND THREE A GUIDE TO YOUR FOLDER



COURSE ADMINISTRATION



- Programme for weekend three
- Contact sheets - details of presenters and facilitators
- Assignment sheet for weekend three

COURSE MATERIALS



- Rites of passage exercise, SHS Trust
- Least Dangerous Assumption
- Parents
- Harry Sutton's piece on Ross



FROM Navin Kikabhai, University of Bedfordshire

- Inclusion Now

FROM MARY SCHUH

- Resources for Scottish Partners
- Notes for Parents (David Pitonyak)
- Consequences of Segregation
- Does Self-contained Special Education Deliver?

Partners in Policymaking

PROGRAMME

Session 3



December 2015

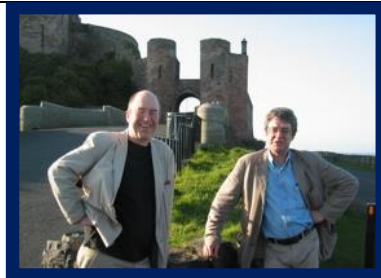
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Friday, 4th December 2015

Inclusive Learning – before, during and after school










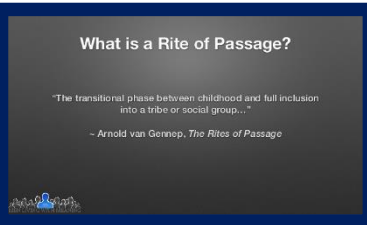


Welcome Back and Feedback -
Jaynie Mitchell and Karen McIntyre,
hearing from you about your assignments







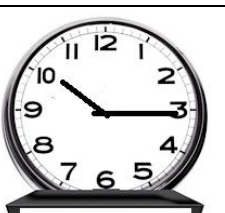



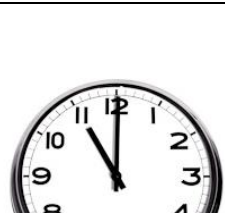

Inclusive Solutions – *Derek Wilson and Colin Newton*











WEEKEND 3 - Inclusive Learning – before, during and after school





 <p>12.30 pm</p>		<p>Lunch</p>
 <p>1.30 pm</p>		<p>Inclusive Solutions – <i>Derek Wilson and Colin Newton</i></p>
 <p>3.00 pm</p>		<p>Comfort Break</p>
 <p>3.15 pm</p>		<p>Inclusive Solutions – <i>Derek Wilson and Colin Newton</i></p>
 <p>4.00 pm</p>		<p>Rites of Passage - <i>Jaynie Mitchell and Karen McIntyre</i></p>

 <p>5.00 pm</p>		<p>Booking into Rooms & Settling In</p>
 <p>6.00 pm</p>		<p>Evening Meal</p>
 <p>7.00 pm</p>		<p>The Alliance for Inclusive Education – Navin Kikabhai</p>
 <p>8.30 pm</p>		<p>Early Close – Christmas Celebrations & Secret Santa</p>

Saturday, 5th December 2015

 <p>8.30 am</p>		<p>Admin Surgery - <i>helping with problems, organising expenses, etc., June Dunlop, Partners in Policymaking Administrator</i></p>
 <p>9.30 am</p>		<p>Key Learning Points - <i>Learning to Listen - Jaynie Mitchell and Karen McIntyre</i></p>
 <p>10.15 am</p>		<p>Responding to Learning to Listen - <i>Jaynie Mitchell and Karen McIntyre</i></p>
 <p>10.30 am</p>		<p>The New Hampshire Experience – <i>Mary Schuh, University of New Hampshire</i></p>
 <p>11.00 am</p>		<p>Comfort Break</p>

 <p>11.15 am</p>		<p>The New Hampshire Experience <i>– Mary Schuh, University of New Hampshire</i></p>
 <p>12.30 pm</p>	 <p>LUNCH</p>	<p>Lunch</p>
 <p>1.30 pm</p>		<p>The New Hampshire Experience <i>– Mary Schuh, University of New Hampshire</i></p>
 <p>2.45 pm</p>		<p>Comfort Break</p>
 <p>3.00 pm</p>		<p>Racheal, Jack & Euan</p>

 <p>3.30 pm</p>		<p>Winding Down and Assignments</p>
 <p>4.00 pm</p>		<p>Close</p>

CONTACT NAMES AND ADDRESSES



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Mary Schuh , University of New Hampshire Department of Education and Institute on Disability.



Derek Wilson & Colin Newton, Inclusive Solutions, 49 Northcliffe Avenue, Nottingham, NG3 6DA
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Navin Kikabhai, University of Bedfordshire, University Square, Luton, Bedfordshire, LU1 3JU
Chairperson@allfie.org.uk

Mary Schuh



Mary Schuh has been with the University of New Hampshire Department of Education and Institute on Disability since 1987, working to coordinate family and consumer leadership and educational systems change. Dr. Schuh has more than 25 years of experience in inclusive schools and communities. She teaches at the UNH and has consulted extensively in the United States, Czech Republic, Slovakia, Belarus, and the United Kingdom on issues related to supporting students with disabilities and their families in typical school and community environments. Among her many projects, Dr. Schuh is the Director of the National Center on Inclusive Education, the Special Education Teacher Certification in Intellectual/Developmental Disabilities academic program, and manages the SWIFT Center's dissemination and outreach efforts where All Means All. She continues in the role of adviser on the award-winning documentaries, Including Samuel, Who Cares About Kelsey? and Lost in Laconia and is the author and co-author of a variety of books and other publications related to inclusive schooling.

Dr Navin Kikabhai

Senior Lecturer in Education Studies



I have a varied range of teaching and research experiences within the education sector. Although I started a career after leaving school as an engineer, lasting for six years, and then decided to return to education. I started teaching in 1994, as an undergraduate, teaching mathematics within a further education college.

My interest, at that time, related to pure mathematics and statistics. Another interest was the forgotten – often, intentionally, excluded – contribution of non-European, disabled people and women in mathematics and music. As a Mathematics and Music graduate, I completed a PGCE (post-16) and became increasingly involved in teacher education and developed a specialism in Inclusive Education and disability issues.

My teaching experience has ranged from teaching mathematics across secondary, further and higher education, teacher education, and teaching units such as pure mathematics, analysis, statistics, research, the politics of disability, disability issues and inclusive education at undergraduate and postgraduate level.

Qualifications

- PhD Institute of Education, Manchester Metropolitan University
- MRes (Education and Social Research), Institute of Education, University of London
- MA (Inclusive Education), University of Bolton
- Licentiate of London College of Music (LLCM)
- Postgraduate Certificate of Education (PGCE – Post 16), University of Bolton
- BA (Combined Honours) Degree in Mathematics and Music, University of Liverpool
- Associate of London College of Music (ALCM)

WEEKEND 3 - Inclusive Learning – before, during and after school

Teaching Expertise

- Education Studies, Disability Studies and Research Method units (undergraduate and postgraduate)
- Student supervision on the MA Education programme.

Research Interests

- European project involving five countries (Italy, France, Romania, Iceland, England) exploring the European legislation and policy context related to Inclusive Education.
- Keynote speaker leading seminars and workshops in Jakarta and Mataram, Lombok entitled 'Moving towards inclusion for teachers of mainstream schools'. He has presented lectures, seminars and workshops in Canada (York University, Toronto), Bosnia Herzegovina, Croatia (University of Zagreb), Indonesia and India (University of Uktal, Bhubaneswar), 2008
- Funded by the Education Attache, Indonesian Embassy to complete a report to explore the scope of educational provision available for disabled young people, 2007
- [EU-India European Cross-Cultural Programme](#) which involved working with colleagues in Germany and India, exploring the notion of relationships, intimacy, friendship and support with reference to 'Circles of Support', 2004-2006
- Conducted an evaluation of a programme 'Partners in Policymaking' (a course which attracts disabled people and parents of disabled people to have an active involvement with their local authorities in order to engage with policy and practice), 2004
- Distinction in the field of 'Emancipatory Research'
- Permanent exclusion of young people from mainstream school.
- PhD situated within the field of inclusive education, disability studies and issues of equality and diversity with a particular interest with disabled students and higher education in relation to the identification of barriers, challenges and opportunities. This work draws upon the theoretical work of Foucault, Deleuze and Guattari which the latter two position mathematics and music as a rarefied form of philosophy, and all three collectively challenge the conventions of modernity and the philosophical tradition of Enlightenment
- 2013 – Keynote Speaker: 'Disability History: Voices and Sources' – organised and hosted by London Metropolitan Archives and English Heritage (22 Mar), London: LMA.
- 2014 – Keynote Speaker: 'Reclaiming Education: Inclusion and equal opportunities need to be at the heart of education provision' Birmingham Council House, Victoria Square, Birmingham, B1 1BB. (15 Nov). Socialist Educational Association (SEA) Review: '...a devastating critique of how the system treats disabled children and the many ways in which the mainstream system denies access to such children. He argued for the dismantling of the segregated system and identified universities as sometimes the worst offenders'. (SEA, 2014)

WEEKEND 3 - Inclusive Learning – before, during and after school

Publications

- Kikabhai, N. (2014). 'Resistance: which way the future?' a dual-screen installation related to the theme of disability and eugenics, *Disability and Society*, 29(1), pp.143-158.
- Kikabhai, N., Kennworthy, J. and Whittaker, J. (2008). 'Inclusive Education and Social Justice in England' in Bunch, G. and Valeo, A. (eds.). *Inclusive Education; To Do or Not To Do*, Canada: Inclusion Press.
- Whittaker, J. and Kikabhai, N. (2008). 'How schools create challenging behaviours' in Richards, G. and Armstrong, F. (eds.). *Key Issues for Teaching Assistants: Working in diverse and inclusive classrooms*, London: Routledge.
- Whittaker, J. and Kikabhai, N. (2005). 'The Illusion of Inclusion', Coalition, *The Magazine of the Greater Manchester Coalition of Disabled People*, Dec 2005.

Research Reports

- Kikabhai, N. (2012). Resistance: which way the future? (Disability History Month Evaluation Report), unpublished, University of Bedfordshire
- Kikabhai, N. and Suwaryani, N. (2008). Exploratory Visit – Indonesian Context, unpublished, funded by the Education Attache from the Embassy of the Republic of Indonesia.
- Kikabhai, N. (2004). Partners in Policymaking – The Wigan Experience, (15 Apr 2008).
- Barton, L. and Kikabhai, N. (2004). Final Report: The [Cutting Edge] Theatre Initiative, unpublished, funded by the Learning Skills Council.

Contact Details

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Colin Newton

MSc. Educational Psychology, BSc. Psychology, PGCE and Special tutor University of Nottingham (AEP, HCPC registered)



From 1998 -2001 Colin was Principal Educational Psychologist of City of Nottingham LEA where he contributed to the consultation on and successful development of an inclusive education policy across the LEA. In 1999 Colin and Derek Wilson collaborated in the writing of ***Circles of Friends*** reflecting some 5 years of training and development work to bring this approach to the UK. In 2001 he co-founded Inclusive Solutions with Derek to promote the mainstream inclusion of all children and adults across the UK whatever their difference, impairment or challenge.

In 2004 Colin and Derek wrote **Creating Circles of Friends** a revised and extended version of the original text including a chapter on secondary schools. In 2006 he co-wrote '**Circle of Adults: A Team Approach to Problem Solving Around Challenging Behaviour and Emotional Needs**'. Colin completed the writing of **Restorative Solutions** – Making it Work together with Helen Mahaffey in 2008.

Colin and Derek recently finished writing and publishing a book entitled '**Keys to Inclusion**' which contains many of the ideas they use when delivering the training day of the same name.

Colin's career has been values driven, but also practical using applied psychology in training and real life problem solving with schools, families and individual children and young people

- From 1989-1998 Colin worked in Nottinghamshire educational psychology service as a senior psychologist in Nottingham city with a specialist role in research and development. During this period Colin co wrote **Managing Change in Schools**, a practical handbook. He led on the development of the 'Bulwell Vision' a community initiative to improve behaviour in a disadvantaged city area
- He spent 5 years in Essex as an educational psychologist
- Colin started out as a primary school teacher in East Anglia and then went on to train and work as an Educational Psychologist in Newcastle
- Colin is a parent to two sons and a daughter





Derek Wilson

MA Psychology, MA Child Psychology

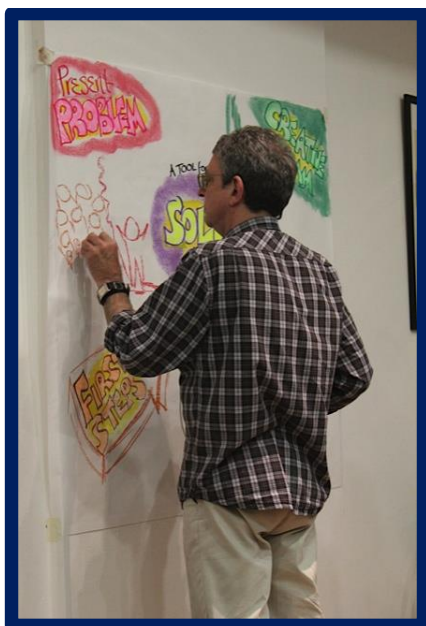


Derek has long-standing expertise and interest in peer support in all its forms and has collaborated in the development of a nationally recognised 'best practice' peer counselling scheme/anti-bullying initiative within a Nottingham comprehensive school. In 2001 he co-founded Inclusive Solutions with Colin to promote the mainstream inclusion of all children and adults across the UK whatever their difference, impairment or challenge. Derek serves on the Council of Management of The Alliance for Inclusive Education. In 2006 he co-wrote '**Circle of Adults: A Team Approach to Problem Solving Around Challenging Behaviour and Emotional Needs**'.

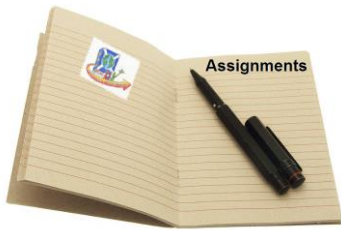
- Derek began his career in special needs education at a special school for children with autism, initially as an educational psychologist and then as Head Teacher
- Derek has been an LEA Educational Psychologist since 1982, he has supported a wide range of special and mainstream schools, developed a specialist Pre School Unit and a LEA Portage Service
- From 1998 -2001 Derek took a lead role in developing inclusive practice within Nottingham City LEA as a senior educational psychologist
- He worked jointly with consultants from the University of New Hampshire USA, successful in gaining DfEE Standards Fund monies to pilot an LEA Inclusion Facilitation Team

WEEKEND 3 - Inclusive Learning – before, during and after school

- Further joint work with the University of Vermont, USA led to the development of a pilot Speech and Language Therapy project, also DfEE funded.
- In 1999 he co-authored '**Circles of Friends**' with Colin Newton and has delivered training on peer support to a wide variety of audiences
- In 2004 Derek rewrote the original text with Colin including a secondary chapter: **Creating Circles of Friends**.
- Derek is a parent to two daughters



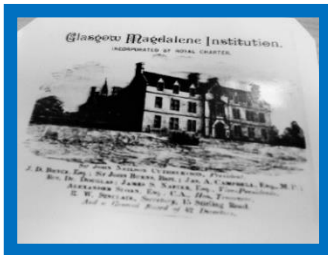
ASSIGNMENTS



So far you have had quite a lot of work to do and we have Christmas and the New Year coming up. This is a chance to recap on work so far to make sure you can catch up.

REMINDERS OF WORK SO FAR:

Assignment 1 October



Finding the local poor house or institution. People brought in material for the November weekend and we stuck it on the wall.

Assignment 2 October



Gathering evidence of positive and negative imagery. Again people brought in their examples and we stuck them up around the room.

Assignment 1 November



Finding out who's who in your local area - hopefully you will have the beginning of a folder full of local information about who's who in your local area. Please keep adding to this through the course - it will become more and more useful. Future use of this material - you will keep the file of contacts for your own reference at present. However, in April when we look at organising change at a local level, we will start to draw up a map of useful contacts across Scotland - so keep adding information and bring it with you in April.

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Assignment 2 November



Thinking about what I want. People were asked to either start work on a Support Plan for themselves or their son/daughter. Alternatively, they had to think about whether a Map or Path would be useful for themselves or their family.

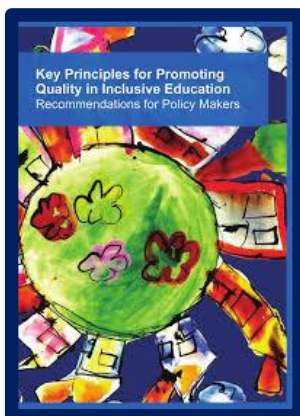
WEEKEND 3 – INCLUSIVE LEARNING before, during and after school

ASSIGNMENT FOR JANUARY

These assignments are optional - you don't need to do all of them and some are not relevant for everyone. However, the more you do, the more you will get out of the course. If you can't cover all of them, pick the one which most appeals to you - or do something else!

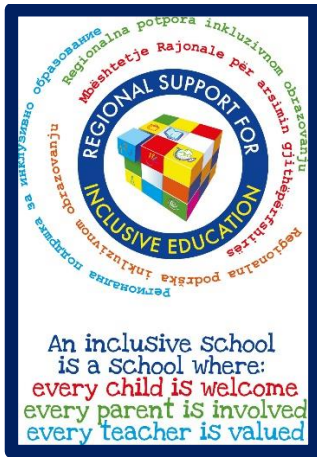
ASSIGNMENT 1

Finding Out About Local Inclusive Education Policy and Practice



We spent the weekend exploring the issue of inclusive education. Your first task is to find out what the policy on inclusion is in your local area. We would like you to contact either the Director of Education locally or, if you feel more comfortable, a local teacher or educational psychologist. You can do this either by telephone or in writing, or by email.

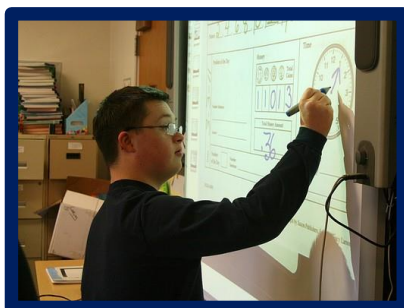
You should start by explaining that you are on the Partners in Policymaking course and that as part of your course work, you are gathering information on your local authority's policy on



inclusive education. You would like to be sent any information they have - whether this is a leaflet, booklet or statement.

It would also be useful for you to have the following information:

- The number of children with additional support needs educated out with the local authority area
- The number of children with additional support needs educated in special school placements within the area and the number of special schools they attend
- The number of children with additional support needs in special school units within mainstream schools
- The trend in provision - are there more or less children in special school placements in the area than 10 years ago?
- Any development plans for the area which would affect children with additional support needs.

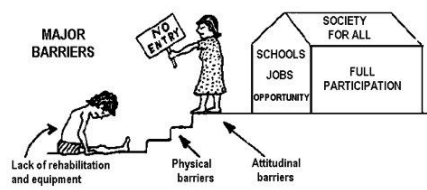


If there are a few of you from one local authority area, it would make sense to work together as a team on this. Get organised - don't send in three separate letters asking the same thing.

rites of passage

OBJECTIVES OF THE EXERCISE

To help us think through what is important to us up to the age of 25 years old. To also help us think more clearly about the real barriers to social inclusion. There are different kinds of barriers and we need to be clear which kind of barrier we are trying to overcome. For example, there are:



- **Intrinsic barriers** – those which are difficult simply because of the person’s impairment
- **Physical barriers** - those which are difficult because of access problems, for example, other people’s houses are inaccessible or the school doesn’t have a lift
- **Social barriers** – Those which are difficult because of other people’s expectations and attitudes

PROCESS FOR THE EXERCISE

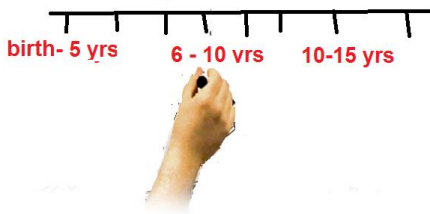


We divide the room up into teams to look at different age ranges, for example, from before birth to 5, from age 6 to age 10, from age 11 to 15, etc. We ask participants in each team to brainstorm ***rites of passage***, which are important for someone growing up in this culture. For example:

- *First birthday party*
- *First day at school*
- *First time having a friend over to stay*
- *First night away from home*
- *First kiss*
- *First drink*
- *First crush on someone*
- *Leaving school*
- *Eighteenth birthday*

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- *Passing your driving test*



When people have brainstormed their ideas, the facilitators will write these up on a long strip of wallpaper with ages from birth to 25 marked along a timeline.

As a group, we the facilitators, will then think about whether the experiences of children labelled disabled are different. We may draw a parallel timeline to demonstrate any key differences. We will then discuss the real barriers between the lines and the forces which keep one person on one line or help someone to move between them.



As a group, we may then reflect on the immediate and long-term impact of being on the parallel track. What do people miss out on and at what cost? The facilitators will then discuss what barriers are the most significant and difficult to tackle and help the group come up with strategies.

TIMING – UP TO ONE HOUR



- 5 minutes - introduction
- 10 minutes - in teams working on 'rites of passenger' for set age ranges:
- 15 minutes - feedback
- 30 plus minutes - identifying barriers (*intrinsic, physical or social*) discussing what's important and coming up with strategies

LEAST DANGEROUS ASSUMPTION

Consider:

Nicholas is 16 years old and has severe disabilities. He is not able to speak, he uses a wheelchair to get around, and has some visual disabilities. The team is not certain as to what Nicholas understands or how aware he is of his environment. Should Nicholas be fully included in regular high school classes?

Scenario 1



We assume that Nicholas cannot understand and is not aware of his environment so we keep him out of most regular high school classes. Ten years from now, we discover that we were wrong and Nicholas does understand and is aware of his environment. What have we lost?

Scenario 2



We assume that Nicholas can understand and is aware of his environment and we fully included him in all typical high school classes, with relevant supports and high expectations. Ten years from now we discover that we were wrong and that Nicholas is not aware of his environment and does not understand. What have we lost?

Lynne Elwell
Partners in Policymaking

PARENTS AND ALLIANCE FOR CHANGE

Alan Tyne - revised September 2003

Stories of parenthood.



In the circles of professionals who work with people with disabilities different kinds of story are common, about the parents of disabled people. One is the story of 'parent as problem' - not accepting their child's disability, grieving the loss of a perfect child, overprotective, over-demanding. Another, only a little less commonly told, is the myth of the super-parent - mystically 'knowing' what is right for their son or daughter, creator of unique solutions, tireless champion, wonderful human being, teacher, inspiration. Lynne Elwell tells of seeing on her daughter's medical notes – "Mother communicates by telepathy"!

The path of differentness

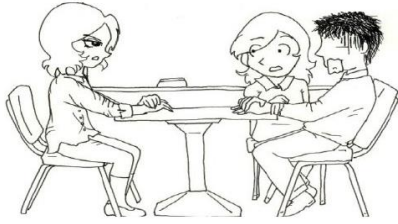


Most of these parents did not chose to be so like everyone else they happened on parenthood, with all the same mixture of inexperience, folk-wisdom and prejudice that most citizens have, about the nature and consequences of disability. They are citizens like any other and they learn from the culture we share. Their lives will have been different from those of other families and other parents, mainly because of the part played in them by disability professionals.



The path of differentness is embarked on early, the search for a diagnosis and the acceptance of special and different solutions that begin to include childcare and schooling, special groups and special classes, special schools and a growing separation between the life of their disabled child and the lives of other children; between their life as a family and the lives of other families. It is not surprising if some families chose to resist in whatever way they know, this inexorable path to differentness.

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It is not surprising if some are seen as 'difficult', a problem, a source of resistance by disability professionals, for they are struggling to retain control in that area every other parent expects as a right to shape their family life and give their children a good start in the best way they know how.

Parents get organised



We have come a long way since the late 1940's when Judy Fryd wrote to a newspaper asking if other parents of 'backward children' might meet with her, and perhaps form an association. The paper refused to "draw attention to her family's shame" by publishing the letter. Later through the pages of Nursery World she formed the 'National Association of Parents of Backward Children', which in time became the MENCAP we all know. The movement of parents and families of disabled people has played a powerful part in the development of the services provided.

In the 1980's Gunnar and Rosemary Dybwad identified four stages in the growth of the movement of parents and families.



- Parents formed together first for mutual support. To be with others who had 'been that way before' made the journey less frightening, gave strength and skills to tackle each stage.
- Shared dissatisfaction with the assistance available led parent organisations to create services themselves, (often reforming 'model' services later picked up by government) and to form the great disability charities. Many became 'bogged down' in the regulations surrounding 'service providers', and over-reliant on their income.



So they were cautious about criticising official policy. Often they became dominated by doctors and academics, and came to reflect 'establishment thinking' and defend the status quo on issues like the institutions and segregated education. Parents were relegated to the role of 'clients' and of course fund-raisers.



- In a third stage groups formed into campaigns to press for policy change. They demanded 'Rights not Charity' and pressed for change in the laws. Parent groups have often focussed their attention around educational reform, and the mass of legislation in the 1990's and 90's reflected the immense diversity of parent interests among other things. These campaigning groups often came into direct conflict with the big charities with whom they vied for influence, and of course resources.



- In the wake of these movements Coalitions of Disabled People formed often they had to struggle mightily to wrest any power at all from the established organisations. But since the 1980's and the growth of international organisations initially through the UN, independent disabled people's organisations have become the major influence on policy development. By contrast, parents, many of them disaffected with the big charities have begun to re-form in smaller, more local alliances working to create unique services or to be heard in the policy forum. They are more inclusive, they have learned from experience, and still they are determined to make a decent life with their sons and daughters. Many have returned again to the first stage, getting together with other families for mutual support.

So the movement comes full circle, but since growth is uneven we see all around us groups at each of the stages, some huddling together for warmth; some busy building new charities; others at the cutting edge of new strategies for personal support and community building.

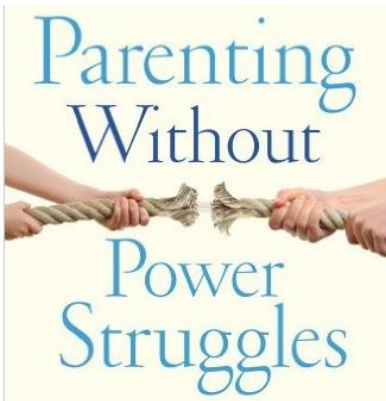
Strength and Weakness



Parenthood is a source of the strength, which flows from passion and belonging. We all know and admire parents who are champions not just of their sons and daughters, but of a whole cause. Parenthood can also be a fundamental weakness.

Each parent is in some sense alone, fighting for what's best for their own child in a chancy market. They take real decisions in a less-than-perfect world, trying to gauge where the balance of advantage lies.

Each family is uniquely vulnerable in the power-struggle with vested professional and administrative interests, to complain too long and too loud might mean losing even what they do have now.



Each family's resources are taxed doubly, they pay as all of us do, then pay again in terms of the demands on their time, energy, space and cash; in terms of uncertainty borne and (often realistic) low expectations of the future. The sheer effort of thinking and planning ahead is sometimes too much. The vision of a desirable future in which communities reach out to include everyone, a vision too distant. It is easy to become stuck in solutions that worked once upon a time, but have long since ceased to function. So, many families accept distorted routines, diminished and dependent lives, because they can no longer see an alternative.



Even when families find some resolution to their personal situation, the story is not over. Change is always shocking. People cling to 'respite' despite its obvious failings and can see no other way to survive. The threat of closure hanging over outdated institutions (long-stay hospitals, daycentres, 'special' facilities of all kinds) revives ghosts long-dead. Problems that had been put to rest years before, (albeit with deep reluctance and little real choice) threaten to re-awaken.

Research shows even families who may have had no contact for a generation with their lost relative are known to go through deep pain and sorrow again at the news of an institution's closure. It is not surprising if they want to chase the homely fantasy of the 'special village' - even though we have long known the quest for the 'good institution' always brings deep disappointment.

One great incapacity of all of us, parents, professionals and concerned citizens lies in our limited ability to listen:



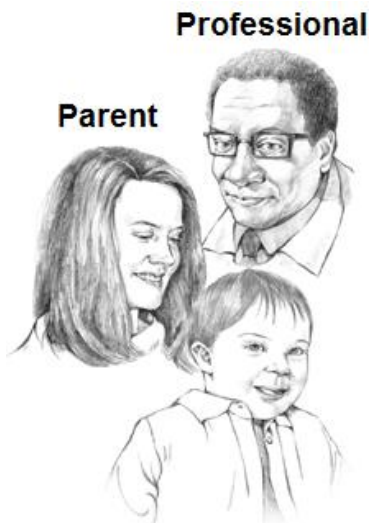
- to what communities have to tell us about what they would like to be
- to what disabled people are telling us about what they have to give
- to what others are telling us of the journeys they have already made.

Fear and pain and tiredness and competition don't make us good listeners. Sometimes we hear only the fear and the pain and hurry into bad answers that offer only spurious safety - in our hearts we knew they would, but it doesn't stop us. It doesn't have to be so.

The safety of alliances



In building any movement for change (whether it be getting better services for our child, or helping other families, or changing the laws of the land) we always have to consider carefully the alliances we make. Chosen with care, our allies help make us safe - alliances give us the space and the time to draw breath, to look around, to seek out others who are travelling the same path.



- Some will be *professionals* - those comfortable enough with themselves not to need always to control others.
- Some will be *parents* - those resourceful enough to be able to work beyond the here and the now.
- Some will be *disabled people* who can see across the narrow boundaries of disability-specific thinking.
- Some will be *citizens* who care enough about the nature of our communities to want to invest in their future.
- *All* will be people who know their own gifts and welcome those they seek and find in others.

Our allies help us listen. As we build our alliances we must be sure no one of these is missing.

As we work for change, one thing we meet again and again, is fear. Sometimes it is the fear of people who may stand to lose from change, they may lose the security of a comfortable routine, the influence that comes with an established position. What is for one person a change in policy that affects their child, is for another a change in their job-routine that may affect all kinds of things.

Many people are frightened to grasp the new because they fear the loss of the old and familiar, for all its faults ("*better the devil you know!*"). Some people will always put their immediate personal comfort above all other considerations. Others will take risks on behalf of others and hardly notice it. Some people fear even to hope, since that way lies the possibility of yet more disappointment. To make real change we have to know and understand intimately the fears of ordinary people. Fear of the unknown then, can be a great barrier to change. Just as powerful of course is our fear of what we all know, only too well:

"if it is to be done, then it is us who will have to do it".

Parents and disabled people have always known in their hearts they must be the change they want to see in the world. But they need not do this alone. Wise alliances give us the courage and the strength to be and to do what we know we can. Wise allies do not bind our imagination, they free it so that we can see the world as it could be.

If we are to make changes, we must learn to listen imaginatively to both the fears and the hopes.

Resources for Scottish Partners

<http://www.swiftschools.org/swifftalk/article/39/counting-everyone-in-the-everyone-category>

17 minutes TedX Talk Disabling Segregation by Dan Habib

<https://www.youtube.com/watch?v=izkN5vLbnw8>

Online field guide with resources to transform schools to inclusive education

<http://guide.swiftschools.org/>

Thaysa video

<https://vimeo.com/55655036>

From this link there are tons of great resources –

<http://www.includingsamuel.com/resources/family>

Notes for Parents

One of the most important lessons that I have ever learned as a professional is that sometimes, in our efforts to provide "special" services to people, we often forget the ordinary things people need every day: friends, family, interesting and fun things to do, safety and security, routine, a chance to be needed (in short, a chance to belong).

Ask yourself, "Is my vision for my child similar to the vision I have for my other children (or the vision other parents have for their children)? When I think about what my child needs, do I focus on disability-related needs or do I think about things like a sense of belonging?"

The following are 10 things to remember if your child is at risk of not belonging because of his or her behaviour:

1. Be Mom and Dad first

Chris Heimerl writes, "Of all the hats you much wear: advocate, care provider, therapist, teacher-the most important is Mom and Dad. Your love is the most powerful treatment any of us can imagine. If all the other stuff you have to do first interferes with being a parent, stop. Someone else can do some of the other necessary stuff, but nobody else can be Mom and Dads.

2. Think of difficult behaviours as "messages"

Difficult behaviours result from unmet needs. In a sense, difficult behaviours are "messages" which can tell us important things about your child and the quality of his or

her life. Obviously there are many needs that your child might be expressing through his or her behaviour(s). A single behaviour can "mean" many things. The important point is that difficult behaviours do not occur by accident, or because someone has a disability, or because someone is "evil" or "irresponsible". Difficult behaviours are expressions of real and legitimate needs. All behaviour even if it is self-destructive, is "meaningful."

3. Don't assume anything

It is easy to make the mistake of understanding your child's potential because of his or her labels or because he has failed to acquire certain skills. This is a tragic mistake. Always speak directly to your child and explain things as clearly as you can. Afford him the same respect you afford to your other children. Never speak about your child as if he was not in the room. Even if you doubt your child's ability to understand your words, know that at the very least your child will understand the tone of your voice; make sure it reflects dignity and respect as often as you can. And always insist that other people treat your child with the same dignity and respect.

4. Remember that relationships can make all the difference in the world

Loneliness may be the most significant disability your child will ever face. Many people with disabilities, young and old, live lives of extraordinary isolation. Some depend entirely on their families for support. A brother or sister or mom or dad are the only source of company. Friends are often absent altogether. Involve your child with other children at a young age (children with and without disabilities). It is easier to learn about the importance of

relationships when their importance has been clear over a life-time. Insist that your child be included in regular classrooms. Inclusion is a powerful way of building relationships. And don't let anyone fool you into thinking that inclusion of children with disabilities in regular classrooms is a bad idea. Doing it poorly is a bad idea. Doing it well is good for all children. Remember that there are many people in the community who will benefit from knowing your child. Chances are your child has already made someone's life fuller. Be confident that she will make someone's life fuller again and again and again.

5. Take care of yourself, take care of your partner, and join with other parents to support each other.

Many parents suspend their own dreams and aspirations the day their child is born. They adopt an identity of "parent of a child with a disability," putting their own needs on hold like a video tape that can resume at the touch of a button. Many parents feel isolated because their child has a disability. They feel obligated to suspend their relationships with other people because the work of parenting their child is all-consuming. Or they feel that other people will have difficulty understanding their child's disability; there can be a deep fear of rejection. As one parent put it, "It is better to be alone than to feel my child's hurt when he is rejected." Chris Heimerl writes: "Take care of yourself, take care of your partner and join with other parents to take care of each other. Before you become a parent you were a partner in a relationship that had enough love, nurturing, and respect to want kids. Don't lose sight of that relationship. Before you were a partner, you were a person that someone found attractive, vital and loving. Don't lose sight of that person." Get connected and stay connected with parents of children with and without

disabilities. Join organizations made up of parents who fight for the inclusion of their children in every aspect of community life.

6. Be assertive and forthright (never let a professional intimidate you).

Professional can be very helpful and dedicated. And some day can be very off-putting. They can use fancy words and credentials to make you feel invisible. Unheard. Unwanted. Don't let them. Never let a professional put you down in a meeting, or convince you that your input about your child is of secondary importance. Your personal knowledge of your son or daughter may be the most valuable information of all. Be assertive and forthright about what you think your child needs. Remember that the vast majority of innovations that have taken place in our service delivery system happen because parents and their children have become dissatisfied with "what is." If you join forces with other parents, you can make a significant difference in your child's life. Learn about the laws and regulations that help and hurt your child's inclusion in community life. Speak up whenever your child's future is at stake. Also remember the importance of supporting professionals when they are helpful; learn to pay attention to their goodness. Above all, be respectful of people who disagree with you while remaining steadfast about what you believe.

7. Help your child to develop a positive identity

Many people with disabilities develop identities as "problem people." They are segregated into "special" programs where they are treated as people who have little to offer. Soon their "treatment" becomes a kind of cage to

protect them from themselves and others. The real danger is that of enough people begin to think of your daughter as a "problem," she will begin to believe it too. We all need to be needed. Help your child to find a way to make a contribution. Start young. Giving is a lifelong endeavour. Things as simple as helping with household chores or helping out at church can teach your child that she can make a contribution. Remember that this is important to overcome the belief that your child has nothing to share. It takes time and determination to help your child and others to see strength and the capacity to give when deficits (neediness) were all that anyone ever saw before.

8. Instead of ultimatums, give choices

Many people with disabilities have little or no control over their lives. Many of the decisions that we take for granted — such as what to wear and whether or not to have a cup of coffee — are made by other people. How would you feel if you lived such a life? The mistake we make with children and adults who have disabilities is that we assume that because they don't always make good decisions about some things they ought not to make decisions about anything. Allow your child to make decision throughout the day. If your child does not speak, ask anyway (suggest that he find a nonverbal way of letting you know what's needed.) Don't assume that helping your child to have more choices means letting him do whatever he wishes. Limit-setting is an important and fair part of any relationship. The real question is who is setting the limits and why. Expect a general disregard for advice when the person receiving the advice is never heard. Rebellion may be a healthy strategy for someone who is out of power.

9. Help your child to have more fun

Fun is a powerful antidote to problem behaviours. Count the number of things your child enjoys; the number of places she likes to go. Compare this to the number of things other children enjoy, the number of places their children like to go. Ask yourself, is my child having fun? Is she experiencing enough joy? Is this an interesting life?" Help your child to add on to her list of interesting (and really fun) things to do. Spend time in regular community places where people hang out. Make a fun goal.

10. Establish a working relationship with a good primary health care professional

Many people who exhibit difficult behaviours do so because they don't feel well. The sudden appearance of behaviour problems can be a signal that your child does not feel well. Illness as common as a cold or an ear ache can result in behaviour as inconsequential as grumpiness or as serious as head-banging. It is important to establish a working relationship with a good primary care physician. Although this is earlier said than done, your child, especially if he has difficulty communicating, will need a doctor who can help him stay healthy and well. Remember too that it is important to go beyond a concept of health as the absence of a disease or illness. "Feeling well" and "being healthy" involves everything from a balanced diet to a good night's sleep. Help your child learn about "wellness."

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