

◆ Inclusive Futures ◆

Issue 6

"Everyone has a right to belong"

March 2000

Nine Key Skills.

In order to support the empowerment of others we need to be able to:

- 1 Recognise people's strengths rather than their weaknesses.
- 2 Respect diverse perspectives and lifestyles.
- 3 Listen and reflect.
- 4 Focus on others, rather than concentrate on our own needs.
- 5 Help people to recognise and become confident in their own abilities.
- 6 Step back and let others take decisions and action - at the right time.
- 7 Analyse power relationships and help others to do so.
- 8 Get good information.
- 9 Analyse the process of what is happening now, and be able to recognise our own role in those processes.

The Family Support and Empowerment Project Cornell University

This UK newsletter goes out free to over 600 people three times a year. contact Peter Bates at batesmp@classicfm.net to go on the mailing list, or phone 0410 439 677.

Campaign for Inclusive Education

The Government plan to introduce a Special Educational Needs and Disability in Education Bill. The proposed legislation will include duties to :

- increase accessibility to education premises and the curriculum.
- make reasonable adjustments to school procedures and practices where they disadvantage a disabled child.

However, the Bill will allow local authorities to continue to segregate disabled children in special schools, if inclusion is assumed to be too expensive or too disruptive to other children. **Send the enclosed postcard to David Blunkett before 20 April or phone 020 7735 5277 for more information.**

A conference called "**End Segregated Education**" will take place at Manchester Town Hall on 10 June. This conference is for disabled people - supporters may attend as observers only. The aim is to build the campaign to end enforced segregation and to support young disabled people and their families. Contact Karen Barton on 01204 903 200 for more information.

Parents for Inclusion

Parents for Inclusion was set up in 1984 and is still run by parents to help each other and spread the word on inclusion. It runs a telephone helpline on 0171 582 5008 staffed by parents who have 'been there'. Parents for Inclusion has a training programme which gives parents a chance to learn how to plan and set goals to help their children 'get a life'. Parents for Inclusion speaks out at conferences, through the media and at local consultations to help make the case for keeping children in our families and neighbourhoods, explaining how we want support to live our lives together. Contact Caroline MacKeith on 0115 942 6809.

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'Adapt the idea.
Don't adopt the model.'
Josette Combes

Introducing Joyce Davidczyk

Our relationship began as a professional one, as she agreed to provide training to a group of families and consumers. Over the last year she has invited me into her circle and I am delighted to be there. Joyce has recently been faced with many challenges that are changing her life. I was recently invited to a gathering at her home on a Sunday afternoon. Everyone brought a dish and it was quite a spread! I was amazed at the people that I met...many of whom I had brushed shoulders with professionally, all of whom I have long respected for their commitment to the inclusion of people with disabilities in my community.

Before we knew it a facilitator stepped forward and we learned of Joyce's needs and wishes. A large calendar was laid upon the floor and people began writing down what and how and when they could support Joyce. We covered everything from transportation and attendant care to getting together to watching old movies and eating chocolate! We continue to communicate via email to coordinate Joyce's supports during this challenging time in her life.

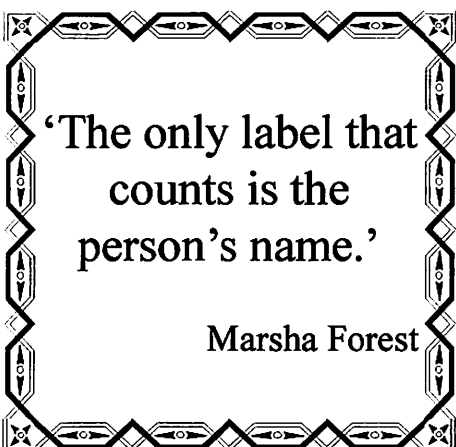
Each member of this group will walk away with something that benefits them, a new friend, a new resource for finding that fantastic veggie lasagna, and the opportunity to contribute to someone else's life. Thanks for letting us in Joyce!

Written by Joyce's friend Debbie Williams

But what if bad stuff happens?

My friend Walter told his story about 'getting out' of the state school, a place he lived from age 12 to age 38. He recalled all the fears, doubts and 'what ifs' that were constantly presented to him by well-meaning professionals. You'll be mugged, abused, in danger, you'll never be able to live independently. Well, Walter does not live independently. He lives with support, like all of us. He and his wife own a home, a van and a dog. He works and has a host of family and friends.

Just about everything 'they' said did indeed happen to Walter. He lay helpless as a thief stole all of his belongings in the night. He was mugged downtown - but he trapped the man with his electric wheelchair against the wall until the cops came. He once fell in a ditch and lay there for three hours before someone found him. Then Walter said, "I would re-live those experiences every day in exchange for NOT spending another day in an institution."



Beyond Special

Olympics... A team of twenty runners with learning disabilities will be taking part in the London marathon on April 16. While individual runners have participated before, this is the first time that a team have entered.

*Schumacher said
"I can't by myself
raise the winds that
might blow us into a
better world. But I
can at least put up
the sail, so that when
the wind comes I can
catch it."*

'Living like other people in the community is not a privilege to be earned, but a right to be enjoyed, irrespective of ability and need.'

Ann Shearer (1986)
Building Community

Aidan's story continues

You may have read the moving story of Aidan in Issue 3 of Inclusive Futures. Aidan's dad recently emailed to share the following update. Thank you, Sam.

It is a crowded Kindergarten classroom, crammed full of books and creative junk of all sorts. Makeshift shelves split the room into work areas where groups of young students pursue their common projects. Two doves, a hamster and some fish make their homes in one alcove; the requisite computer is squeezed into another corner. It is a fun and lively place. But narrow aisles leave little room for our son's wheelchair and my wife and I worry that Aidan might not fit.

Indeed, fitting Aidan into a classroom or a neighbor's house or anywhere is a constant worry for us. He is multiply and profoundly disabled. He cannot see, speak or walk. For no known reason, his brain did not develop normally in the womb. Though seven years old, he has the physical and mental capacities of an infant. He will never earn an "A" in school, throw a baseball, or sing a song. How can he possibly fit, physically or otherwise, into this regular kindergarten class?

We should not be worried because Leland is here. Leland had been in Aidan's pre-school class and is always first to volunteer to push Aidan's chair or to sit next to him at story time. He knows that Aidan likes to feel things in his hands. On the playground, Leland finds stones or plants to rub across his friend's palms. We often discover tiny treasures - dandelions, pebbles, dried leaves - lodged in the chair cushion, evidence of Leland's playful assistance. When the time had come to move up to Kindergarten, Leland asked to be in Aidan's room, to be near his buddy.

But that was pre-school, where more attention is paid to socialization. This is Kindergarten, where the other children will have to advance in their studies. They will begin to read and write, things that Aidan will never do. And as they grow intellectually, the social distance between them and Aidan will likely grow as well. They will notice what he is not doing, what he cannot do. Perhaps, they will start to see him in a different light. I have seen it in the older students, the fifth and sixth graders. In the morning, as they amble past the door where the van drops off the kids in wheelchairs, they comment, sometimes harshly, about the "handicaps." They are not bad kids, just unaware of the hurtful power of their words. This is what we fear about Kindergarten: the beginning of the end of our boy's innocence, his introduction into a demanding and fast-paced world that will only seldom slow to appreciate him.

It does not take long to allay our fears. In a few days, the cluttered classroom is rearranged to make room for the wheelchair. Aidan is included in most facets of the class. When the other children are reading aloud, he is nearby, listening in. At craft time, his teacher's aid makes sure that his hands, too, are doused in finger paint or smeared with glue. Although he must lie down on the couch when he is uncomfortable, the other children do not see this as odd or disruptive. They do not find it strange when his physical therapist comes into the room, lays him down on a mat, and stretches his arms and legs. Gradually, one by one, they take an interest in him, and that grows into understanding, which blossoms into affection.

During the second full week of school, Aidan's class is in the gym to play dodge ball. They choose up sides, and Nicholas, one of the captains, picks Aidan for his team. Then, without any prompting from anyone else, he stops the selection. Turning to his

classmates, he calls out: "OK everybody, let's do three cheers for Aidan." And they do. Each child adds a voice to the cheerful chorus of "hip-hip-hoorays" that echoes through the cavernous room; and each flourish affirms Aidan's place in the class.

Such moments stand in stark contrast to the isolation that might have befallen Aidan had he been born in a different place or a different time. I am confronted with such ominous possibilities when we drive to my mother's house. The trip takes us past an old state mental hospital. It is a sprawling campus of forlorn red brick dormitories, rusted brown bars on widows, colorless paint flaking into oblivion. The institution is not used much these days, only a few people ply the weed-choked pathways, but it stands as a melancholy monument to the time when severely disabled people were shut away from society.

But that is not Aidan's life. Instead, he has his place in a chaotic Kindergarten, where he can feel a hamster scamper on his lap and sense his friends around him. His wheelchair may sometimes collide with a bookshelf, but he is a full-fledged member of the class. He fits.

George T. (Sam) Crane
Department of Political Science
Williams College
Williamstown, MA 01267 USA

“We cannot reach health by understanding illness. The language of science alone is insufficient to describe health: the languages of story, myth and poetry also disclose its truth.”

Michael Wilson

Employment...

On 20th November 1999, 34 people were awarded a Diploma in Supported Employment at Oxford University. The Diploma aims to teach people how to provide effective support for disabled people so that they get and keep a real job. After 12 months hard work, Steve Leach was one of those who received this award and was asked to give a speech at the awards ceremony. Here are some extracts from his speech.

"I soon realised that the Diploma offered more than just a few useful ideas to enhance our service. It was quite a revelation to find a comprehensive strategy that could bring together all the parts of our employment service into an effective and structured whole. For a professional development diploma to be based on the rights of the individual, on self determination, the concept of inclusion reducing the role of the professional from the fount of all knowledge to that of a facilitator, seemed to me to be a radical and welcome move.

I was surrounded by a large group of intensely enthusiastic and committed fellow students. They fervently advocated an approach that supported the civil rights of people with disabilities in becoming full inclusive members of our society

The Diploma offers a mix of theory and practice that allows you to take an individual approach whilst keeping in mind the basic principles of self-determination and client centredness. The materials are excellent, they are well thought out,

comprehensive and obviously developed by people close to the coal face.

Schon in his book "Educating The Reflective Practitioner" used the term 'professional artistry' to refer to the kinds of competence that practitioners sometimes display in unique, uncertain and conflicting situations of practice. In supported employment we need to exhibit this professional artistry in the countless acts of negotiation, support, judgement and skilful performance necessary to achieve successful progression.

We are guides, offering information, advice and support which enables an individual to focus on their own skills, preferences and aspirations to make their own employment choices. It won't always work out and there will be failures but that is part of the learning process. Try another way! to reiterate Mark Gold's legendary maxim.

Inclusion is a crucial development area for our society.

At Scope we recently won some Government funding to look at the use of the Supported Employment person-centred strategy within our supported employment programme (SPS).

The Diploma is undergoing a management change at present but information about future courses will shortly be available.

Steve Leach, Employment Officer & SEP Project Co-ordinator at Scope will have up to date information. Tel 01924 366711. email: steveleach@compuserve.com

Whilst Scope is a voluntary sector organisation for people with cerebral palsy and related disabilities the aim of Scope's Employment Services is to assist all people with disabilities to progress as far as possible towards sustained, integrated employment."

Congratulations, Steve!

James was originally placed as a YTS trainee requiring special support with a local council in 1988. He has dyslexia and at the time lacked confidence in his own abilities. He started as a junior clerk in the building and construction department. He started to use the computer and progressed so well that in 1991 he was assessed as being able to work in unsupported employment. He became a full member of the council's staff, started a college course in building and was promoted to junior technician. He is now a technician in the bridge design team and has achieved a Higher National Certificate in Building.

From the DfEE good practice guide to employing disabled people, p 13

Questions to ask your school...

- *Do you serve all children in the area?*
- *Do disabled pupils attend the same school that they would go to if they did not have the disability?*
- *Is the disabled pupil's school day (length of the day, times of arrival and departure) the same as the school day for pupils without disabilities?*
- *Do timetables and written materials about the school promote the inclusion of all children?*
- *Is there annual in-service training on inclusion for everyone?*
- *Do disabled pupils participate in extracurricular activities with pupils without disabilities?*
- *Are curriculum materials age appropriate? Are curriculum materials used by pupils with disabilities of the same chronological age as those for pupils without disabilities?*
- *Does learning support match the pupil's strengths, needs, preferences and interests?*

The Government have produced more than 20 different leaflets giving information about aspects of the Disability Discrimination Act. Order a catalogue by phoning 0345 622 633.

Tiea's Gift

David was 3 years old and he would often hang out with Tiea at the pre-school playgroup. Tiea is blind, cannot move, has epilepsy and cannot speak. Adults couldn't see what David saw in her - so they asked. David said that Tiea was great at keeping secrets - he told her his secrets and she never told anyone. David had found her gift, seen past the disability to the whole child.

Circles

Circles Network (UK) has appointed Christine Burke as Regional Co-ordinator for London and the South East. Christine has had a long standing relationship with Circles Network and is now developing a regional plan to take the work of the organisation forward in the South. If anybody is interested in helping they can contact Christine on 0181-985-5225.

Circles Network has launched a new publication. Called 'Inside Out', the book explores lifetime learning, how it differs from traditional ideas about learning and how to make a start in documenting (for yourself and others) personal gifts, talents and achievements. The book gives some examples of projects that are supporting people to gain confidence in their own abilities through creative means. It is easy to read, well illustrated and contains a wealth of material that supports the development of person centred planning. Contact Christine Burke.

Volunteering page

The Volunteer Bureau in Burton upon Trent has been working to ensure that people with mental health problems have an opportunity to become volunteers. To help with this, they created an exhibition of artwork and poetry by mental health service survivors. The Exhibition toured a leisure centre, a library and a hospital during October and November 1999.

Jan wrote, "I've had anorexia for twenty years. I used to feel useless, worthless, not needed by anyone. Through volunteering I feel part of something. I would recommend volunteering to anyone. It's done me the world of good and I'd be lost without it."

Contact Belinda or Vicki on 01283 515 765.

"Although.. some friendships may be characterised along similar themes, our research also showed that individual relationships are unique. Thus, professionals or others may be unlikely to succeed in facilitating new socially stable relationships by trying to create precise 'matches' between individuals with disability and other community members. It may be better to help individuals meet as many people as possible, under the assumption that sooner or later one of the relationships with 'click' for reasons that might never have been predicted.

Slightly adapted from J. Stephen Newton, Deborah Olson and Robert Horner (1995)
Factors contributing to the stability of social relationships between individuals with mental retardation and other community members.
Mental Retardation Vol 33, No 6 pp 383-393.

*Please excuse the use of the word 'retardation'.
It's a word that lots of doctors use in America.*

"Disabled People and Volunteering" is the title of an information booklet produced jointly by SKILL (the National Bureau for Students with Disabilities) and the National Centre for Volunteering (tel 0171 274 0565). It is full of useful advice about how volunteer organisations can be accessible to people who need a bit of extra support. Here is one idea they have tried.

"Partnership volunteering"

Two volunteers work together and support each other. Both volunteers can be new to the work, or an existing volunteer might be willing to be a partner for either a shorter or longer term.

The booklet gives an example as follows. "A school leaver was interested in sport but was very shy. He worked alongside a partner volunteer at a community recreation play scheme. After being introduced to the work by the partner volunteer, he began to attend the scheme independently."

First Class first aid!

Andrew Boulton applied for a Millennium Award from Mencap to learn about first aid. He received five hours a week support for six months. Together, Andrew and his supporter gradually converted a first aid manual into pictures and symbols so that Andrew could easily follow the course. By the time they got to the one day course Andrew already knew most of the answers and he passed with flying colours.

Jumping for Joy!

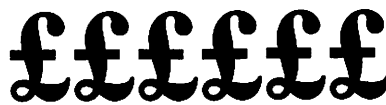
When he was asked what he wanted for his 23rd birthday, Paul Wilcox told his parents that he wanted to do a parachute jump. The team at Hinton Sky Diving Club were really confident and professional. Nobody said whether they had ever done a jump before with someone with Down's syndrome, but they showed Paul what to do and seemed full of confidence. Jumping from 12,000 feet seemed totally cool as far as Paul was concerned and he enjoyed every moment of it, as well as raising £400 in sponsorship money.

Realife

The Realife Network has been funded by South Essex Health Authority to help build more inclusive communities for people with a learning disability in the Brentwood area of Essex. We believe that building support circles, nurturing more naturally inclusive communities and being totally person centred are essentials if people with a learning disability are to achieve their hopes and dreams.

For further details contact Sheila Ward at Realife,
3 The Courtyard, Bishop's Stortford,
Herts CM23 2ND.
Tel 01279 504 735.

The Ragamuffin Project uses interactive theatre to take disability awareness into primary schools in Swansea and Camarthanshire.



The European Commission has adopted an EQUAL programme backed by £1.75 billion over six years to back schemes which help people into work, such as skills training, accessible communications and creating accessible buildings and transport. EQUAL projects start this year and will gradually replace funding agreed under the Employment Horizon Initiative.

 ★ *Talkoo is a word from Finland.* ★
 ★ *It refers to the village* ★
 ★ *tradition whereby people work* ★
 ★ *together without pay for* ★
 ★ *mutual benefit: for example,* ★
 ★ *by harvesting, logging or* ★
 ★ *constructing buildings. The* ★
 ★ *work is sometimes done for* ★
 ★ *individual families and* ★
 ★ *sometimes for the whole* ★
 ★ *community: for example, the* ★
 ★ *building of a village hall.* ★
 ★ *When the work is completed,* ★
 ★ *the host family offer food and* ★
 ★ *drink, and there is dancing* ★
 ★ *and singing. Talkoo work* ★
 ★ *grows communities.* ★

HIGH DRAMA

The Lawrence Batley Theatre in Huddersfield is the first mainstream theatre to host a resident company of adults with learning disabilities. The main theatre has won an award for accessibility. Box office 01484 30528.

Joy for the Weary

I find myself called on to work with lost and lonely souls, youthful lives being cast aside by an inept system that would rather blame the child than look to their contribution in sealing the fate of the child. The skills I bring to the youth I serve help me teach them to put their pain and anger in perspective. I teach them new ways of responding to a world that had previously confounded, confused, and enraged them. And sometimes I don't know what to do, what to teach, or what to say. All I can do then is love them and let them know they will not be abandoned. I don't have the fast track on caring and helping kids. There are many who share my passion and compassion for kids, but who do so from different yet effective vantage points. If you know something I don't about serving kids, I need to know what it is. I might have something to offer you as well.

I realize I've taken this debate out of the academic arena and made it personal. But it is personal for me. If it weren't, I would have nothing to offer the youth who, in those rare moments, look to me for guidance. And when they do, I need to give them the very best there is, no matter who staked the claim to the idea. But that's where we come full circle to science. I depend on that science to keep me from fooling myself. It keeps me coming back as a critic of my own work to ask, "Did what just happened, happen for the reasons I claimed?" "How do I

know I am not fooling myself?" To these questions I am accountable.

Debates are meaningless and useless if you can't take them into the run-down estates, the back alleys, the corn fields, or any where else and make the dull shiny, the wilted green, and the weary joyful.

Stuart R. Harder

"We cannot wait for great visions from great people, for they are in short supply at the end of history. It is up to us to light our own small fires in the darkness."

Charles Handy 1994.

Now listen carefully...

"While in Zimbabwe setting up a business, we had to call on the manager of a large hotel and so we parked our car on the road. A bunch of young children were hanging around the area. When they saw me, one 10 year old approached and asked if he could look after the car. I thanked him, but said it was not necessary. My colleague Leonard, however, said that he would like the youngster to keep his eye on it, and "would see him later".

I asked the manager about the children. He looked exasperated and said they were

becoming a real nuisance. They were now intimidating customers who refused their services, and in some cases cars had been badly scratched. I asked him what he was going to do. He said, "I suppose I will have to call the police to deal with them." Leonard then asked, "But what do these kids want?" He said he had no idea. "Have you asked them?" Leonard responded. "No!" he replied. "Would you like me to find out?" He agreed. Leonard wandered out to speak to them. He is black, African Caribbean, and had 'street cred', having grown up in similar circumstances as the youngsters. Leonard came back and told the manager, "They want to go to school." Within a few months Leonard had helped the manager to send some to school. He also employed them to look after cars at the hotel on weekends and gave them badges to wear. The vandalism stopped and the community as a whole benefited.

John Carlisle, Sheffield.

"We cannot reach health by understanding illness. The language of science alone is insufficient to describe health: the languages of story, myth and poetry also disclose its truth."

Michael Wilson