



NEW WRITING

An Alphabet of Helpful Hints:

For new practitioners offering family-centred support to children with disabilities / special needs

By Peter Limbrick

This is a regular feature in IQJ. The alphabet covers issues which have arisen repeatedly in my consultancy and training work over the last 12 years. The suggestions humbly offered here come from my experience as a sibling of a man with severe cerebral palsy, as a teacher of children with disabilities / special needs, and as a keyworker in the 1990s with families of neurologically-impaired babies and young children.

D is for Dependence

There is not one single person who can stand aloof claiming to be independent. There is not one single person who is not helping meet some needs of some other people.

Readers might have expected me to wait until the alphabet reaches the letter 'I' in April 2010 so that I could talk about 'I for Independence' (while other readers will be wondering what I am going to do for 'X') but I want to argue here

that independence is never a valid or achievable goal and that dependence is a fact of life which should be acknowledged, embraced and nurtured in our own lives and in the lives of people we are caring for or who care for us.

When we talk of independence I think we usually mean autonomy – which is different. Here is an example of the difference. Imagine you are in a lift in a hotel. You are dependent for going up or down on the motor driving the lift. You could argue that you could be independent and take the stairs but then you are dependent on whoever keeps the stairs clean, safe and lit – and will you manage the luggage? Whatever your skills and abilities you can be autonomous if the lift's control panel is designed so that you can understand what you have to do and can reach the buttons. So you are fully dependent on the lift but you can still be autonomous in getting where you need to get to.

Perhaps you are with someone else and you are moving in to the Honeymoon Suite on the top floor of the hotel. Whatever abilities and disabilities the two of you have, you can be autonomous in using the lift if at least one of you can operate the controls – even though you are both dependent on the lift to carry you up to the top of the skyscraper. Being autonomous does not have to mean being alone!

'Ah,' you might say, 'But it is very different being dependent on other people from being dependent on machinery!' Perhaps it is not so very different. (And anyway, we are dependent on people to make the machines.)

After you have read this article you might call a taxi to take you to the theatre. You will be dependent first on the taxi driver, then on the front-of-house staff and then on the actors for a safe and pleasant evening. You will achieve autonomy if the taxi takes you to the theatre you want to get to at the proper time, if the ticket you bought in advance is a valid ticket and if the actors are performing the same play that you bought a ticket for. Next week I will probably be dependent on a barber to cut my hair and, in years to come perhaps, on someone to help me take a bath. Being dependent on both people, I shall have autonomy if the barber cuts my hair the way I want and if the person helping me bathe is of my choice, if the bath happens at the time I want it and if he or she lets me have all my boats in the water with me.

Dependence, as I see it, is an inescapable fact of existence. Here is an illustration to develop the argument a bit further. I have in mind a small, simplified, imaginary, rural community. There is a baker, a brewer, a blacksmith, a healer, a school teacher, a carpenter, a farmer, a priest, a maker of bricks, and others. At some point in the lives and deaths of each of these people each one will be dependent on the products, services and help of most or all of the others. It is not a linear chain of dependency – it is an elaborate, rich and ever-changing network in which each person is linked in mutual dependence to all of the others. The villagers are interconnected and interdependent and it is this mutual give-and-take that keeps the community alive and makes survival possible for all of us on this lonely planet.

In the interdependent social structure of village, city or nation we are all, regardless of our abilities and disabilities, in the same boat of taking from others what we need and offering to others what they need. There is not one single person who can stand aloof claiming to be independent. There is not one single person who is not helping meet some needs of some other people. In our interdependent world the boundaries between 'abled' and 'disabled' dissolve away completely and we can see the illogicality of 'us' requiring 'them' to become

independent – or of 'them' setting independence goals for 'us'.

But if we take independence training off the timetable in school, college and care home what is left for those of us who want to promote relevant learning in others or in ourselves? Absolutely everything – but with a more focused, realistic and empowering intent.

Just as, in a caring society, we are helped to preserve our autonomy, our self-governing behaviour, as we lose skills because of illness or infirmity, so as we grow up, we are helped to develop autonomy in our expanding world. Babies, children, teenagers and grown-ups, on our own or with help, can 'know' (with varying degrees of awareness) what we are ready to learn next. (As an early intervention teacher/keyworker in One Hundred Hours I found that neurologically impaired babies would always teach me what they were ready to learn next – as long as I was paying attention.) This process of deciding the next learning task is itself a rich and imponderable mix of developmental stage, skills already achieved, relevance, motivation, personality and spirit, and the outcome might be an attempt to achieve teeth cleaning, scuba diving, computer programming or holding a spoon at mealtime.

It seems sensible to recognise that none of these new skills will bring an end to mutual dependence; the trained diver is dependent on people in the support boat above, the computer programmer is dependent on computer manufacturers and repairers, the teeth cleaner is dependent on manufacturers of brushes and toothpaste and on a water supply, the spoon holder is dependent on someone to prepare the meal and, perhaps, load the spoon.

While acknowledging that the person with the new skill is still a mutually dependent being, we can explore to what extent she or he can be autonomous in the new activity, and if the new skill adds to the degree of autonomy the person enjoys in general terms in their life. Can the scuba diver choose when and where to dive, and with whom? Can the teeth cleaner choose the toothpaste and his next new toothbrush? Can he clean his teeth whenever he feels the need? Can the computer programmer opt to convert the new skills into a business venture? Can the person holding the spoon choose what goes on the spoon and when it is lifted to her

mouth? Surely it is these elements of autonomy that bring improved wellbeing and quality of life – and without which the new skill could soon become irrelevant and redundant.

Interdependence brings another aspect of learning into sharper focus. By this logic we should be preparing ourselves and others for a life, not of independence and splendid isolation, but of mutual give-and-take in social networks in which everyone has something to offer and everyone depends on others for different things at different times. The elements of this learning and preparation will include communication, listening, empathy, turn-taking, sharing, self-valuing, valuing others, negotiation, etc – all the things that create bonds with the other people with whom we share the classroom, the care home, the shopping precinct, the workplace, the planet.

What can interconnected interdependence mean for new families with neurologically impaired babies – and for the practitioners who work with them? What can be done to encourage supportive networks? Here is a short list as a start. I am sure readers can add many more:

1. It can mean that part of our task is to nurture not just the child, but the parent on whom the child depends for everything. It can mean we explore who is supporting the parents as they support their child. (For example, would grandparents be more able to help if they were given some training in managing crises or handling medications?)
2. Can we help parents by supporting their aspiration (in very practical terms) for young siblings to have a good quality of life?
3. Would friends, neighbours and extended family be more understanding and supportive if parents were helped to find honest and uncomplicated ways of telling them all about the child's needs?
4. Can we locate some relevant, timely support from other parents with children in similar situations (in the flesh, on the phone, online)?
5. Should we acknowledge that some (most?) parents of neurologically impaired babies need to gather confidence, strength and resources from

smaller, supportive services and networks before they are ready to launch themselves into fully integrated living in the bigger world?

6. Are there parents who need help to gain improved skills in dealing with service providers – skills in communication, negotiation, positive thinking, assertiveness?
7. Do the practitioners who are supporting parents need some support for themselves?
8. Should practitioners acknowledge that they cannot 'go it alone' with these children and families and that they can only function effectively in mutual dependence with the other key people who also work with the child? This is the Team Around the Child (TAC) philosophy within which there is the concept of collective competence. By this thinking, for example, neither a mother, a visual impairment teacher nor a physiotherapist can think themselves competent as a separate individual to offer a whole approach to a blind infant with cerebral palsy. The three are dependent on each other to achieve collective competence in close collaborative teamwork.

No man or woman or child is an island. No person is independent of other people and it is false to hold up independence as a desirable or achievable goal for anyone. We are all in the same boat. Whatever our abilities or disabilities we are all dependent on each other. This is the glue that keeps us together and makes life worth living.

Discussion welcomed. Let me know if you would like some references for authors who write about mutual interdependence. Contact p.limbrick@virgin.net

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