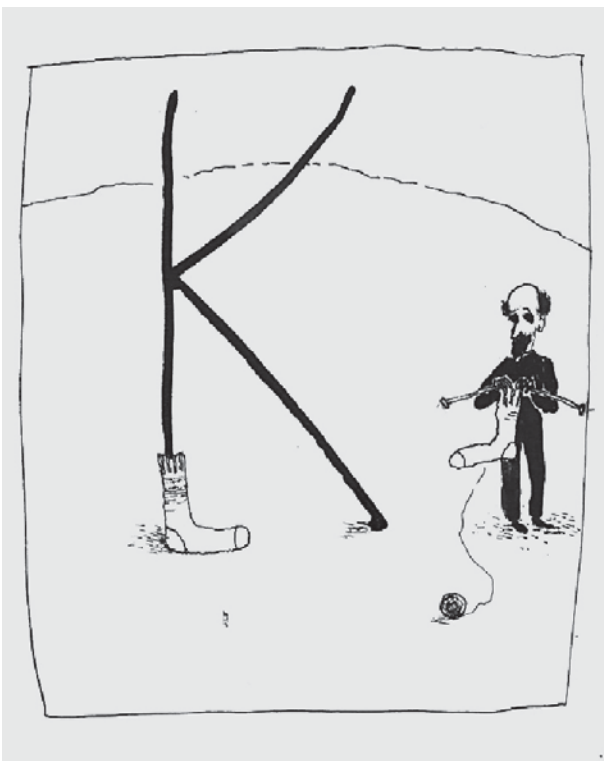


An Alphabet of Helpful Hints: K is for Keyworking

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As a UK practitioner in the field of childhood disability, you might have been, or become, or already be, a keyworker or lead professional for one or more children and their families. In this alphabet piece I want to talk about what keyworkers might do and what support they need to enable them to do it.

The ideal for me is that each individual child, young person and family will have just one multi-agency keyworker (rather than a separate keyworker from each agency or service that supports them) at the times when they feel the need. Again, ideally, keyworking support will be available from birth through adult life, but, in the context of IQJ, we should be thinking of keyworking being available to a child from babyhood to entry into adulthood.

There are two types of keyworker, designated or non-designated, single role or shared role. There are pros and cons to both ways of keyworking. The designated or single-role keyworker works with each child and family in the sole capacity of keyworker, with keyworking being the whole of her job description. (I shall continue in this article to refer to keyworkers as female though I realise it is only a generalisation.) The other type of keyworker, the non-designated or shared-role keyworker, will have another main role in her job description, e.g. therapist, teacher, nurse, health visitor, social worker, nursery nurse, Portage worker, and might well perform the dual function with each child and family for whom she has taken on the additional role of keyworking.

In this article I am going to refer to a keyworking model that was developed during the 1990s by the Yorkshire charity, One Hundred Hours (OHH). This organisation was one of the pioneers of keyworking (alongside other successful projects, two of which were in Ceredigion and Pembrokeshire) for disabled children and their families. OHH offered a free keyworking service to families of neurologically impaired babies and pre-school children and employed experienced practitioners (teacher, social worker, health visitor, learning disability nurse) as single-role keyworkers, i.e. they would have just a keyworking role with each child and family.

Rather than tell families what their keyworker should do, we developed the role in response to parents' wisdom and we gradually shaped our keyworker job description in response to the things they were doing with children and families and the needs they were meeting. But, it is fair to say, when I started OHH, as a teacher of children with multifaceted conditions and 'complex' needs, I imagined our main role would be focussed on early interventions for the infant. By the end of the decade it was clear that supporting parents in a child- and family-centred approach was OHH's main required function.

What do keyworkers do?

OHH came to define the keyworker as '*a source of support for the families of children with disabilities and a conduit by which other services are accessed and used effectively*.'^{*} In later years, the English government's Early Support project adopted the definition, changing *conduit* to *link*.

A fuller definition and a summary of the role of OHH keyworkers is as follows:

The keyworker is both a source of support for the families of children with disabilities and a conduit by which other services, including treatment, therapy, education, respite and benefits, are accessed and used effectively.

The role of the keyworker can be summarised as offering support, information, advocacy and co-ordination. Specifically, the keyworker will make available the following elements of support:

- giving **emotional support** to parents and other key family members. Counselling skills are used but the keyworker is not providing formal counselling. The major element of this support is 'active listening'
- helping the parents get **answers to their questions** about the child's condition
- helping the parents get **information** about all relevant services and benefits
- helping the family get **all relevant services**
- helping the family to **promote the child's well-being**, play and development
- helping parents **co-ordinate the professionals** and agencies involved so that
 - appointments are rationalised
 - professionals know what each other is doing
 - parents are not overloaded with things to do
 - duplication and contradictory advice is avoided
 - services provide collectively for the whole child and family
- helping parents **integrate all interventions** so that
 - they have a holistic picture of the child's abilities and needs
 - there is a whole approach which embraces all developmental activities, learning programmes and goals
- promoting parents as **equal partners** in all services to their child

Importantly, the precise nature of the input, i.e. which elements are selected from the above list, is decided by the parents in consultation with their keyworker.

Thus parents are not given a predetermined service but are enabled to design the service that is right for them and their individual circumstances at the time.

What do multi-agency keyworkers need?

Keyworking is a highly professional job. When I was a keyworker in OHH I found it the most demanding and multifaceted role of my career up to that time. At the same time, it was by far the most rewarding and fulfilling. I felt it was a great privilege to be asked by parents for support and to be invited into their homes and their lives. Keyworkers most certainly have particular needs to help them function effectively and to look after themselves in this potentially time-consuming and stressful role. The list below applies to designated and non-designated multi-agency keyworkers.

Keyworkers need a properly joined-up service to work in

Children, young people and families, when they are supported long term by a number of practitioners, services and agencies, need it to all be properly joined up. Otherwise they will be subject to disorganisation, fragmentation, a piecemeal approach and, sometimes, a fair amount of unhelpful chaos. Rather than thinking naively that a keyworker can step in single-handed and get local services all joined-up into a seamless approach, we must acknowledge that this is beyond her power and capacities. In fact, keyworkers themselves need a joined-up environment to work in. If this is not the case, the keyworker will be subject to the same messy disorganisation as the child, young person and family – and can become ineffective and subject to stress at work.

Keyworkers need good management, back up and supervision

When local agencies and services have worked together to create a well organised, joined-up multi-agency support system for disabled children, young people and families, they must build into it a management system for keyworkers that oversees their work and offers back-up when necessary and regular supervision. Keyworkers will often find themselves supporting families in very challenging situations that can involve discrimination, animosity, depression, illness, uncertain life expectancy and death, and must not be left to feel they are out there on their own.

Keyworkers need training

This will include initial training at the beginning of the keyworking role and then regular training and team-building sessions on particular topics after that. Much of keyworking, perhaps all of keyworking, is based in relationships – between the keyworker and family members and between the keyworker and local practitioners also involved with the child, young person and family. Personal relationship skills are essential as are skills in partnership working and negotiation.

Keyworkers need good, up-to-date, local knowledge

While we often hear parents of children and young people who have disabilities and special needs speak despairingly of having to find their way through a maze of local services, in my experience local practitioners are just as much mystified about what the other services and agencies offer and how to access it. What hope is there then for the keyworker who wants to tell families what help is available and how to get it? The answer must be a local collective effort to put everything onto a website that is kept up to date and available to practitioners, disabled children, young people, families – and to keyworkers.

Keyworkers need time and clerical support

Time must always be an issue. Some families are in challenging situations that will require much time from their keyworker – perhaps for a listening ear, perhaps for complicated service co-ordination. Other families will need increased time when they are facing a transition or in the middle of a crisis. Often these time demands are unpredictable. This means that some sort of time flexibility must be built into the keyworkers' management system. Obviously, non-designated, shared-role keyworkers will need extra consideration as they juggle the keyworking demands alongside the on-going requirements of their main role as therapist, nurse, etc. All keyworkers will benefit from administrative or clerical help with contacting the local agencies, services and practitioners around the child, with setting up meetings, and with writing and distributing minutes, reports, action plans, etc.

To finish off with and, at the same time, to demonstrate the great importance of keyworkers, here are three quotes from OHH families:

1. *One Hundred Hours helped me through a grieving period and allowed me to cry and be selfish. I did not feel I had to pull myself together or pretend I was coping.*

2. *I can honestly say I would have had a breakdown without One Hundred Hours – they have given me so much to believe in with [our daughter]. They have told and shown me how to enjoy (our child) as her mother and not a nurse. (Our child) has come on so well, being introduced to OT, physio and speech therapy all through One Hundred Hours. Now they are helping me with assessments at (the CDU) and schooling needs.*

3. *We met One Hundred Hours the day we brought (our son) John home from the neonatal ward after he had spent five months fighting for his life.*

With the help of our keyworker, we started to understand John's problems and our confidence grew. Thanks to all the information and ideas, we became confident partners with other professional services

and could articulate John's needs and best interests.

Our main needs are to overcome our 'disability as parents' and discover ways of recharging our limited batteries. We need to maintain our relationship as husband and wife and not lose our self-esteem, confidence and the ability to enjoy our life or the courage to try new challenges. The value of One Hundred Hours is that it helps parents find a way forward using our own strength and the love in the family.

* The quotes about One Hundred Hours are taken from the publication, Limbrick-Spencer, G. (2001) *The Keyworker – a practical guide*, Birmingham, WordWorks in association with Handseltrust.

Note: At the end of the 1990s, One Hundred Hours, lacking any financial support from national or local government, wound down its work with families and became the Handsel Trust which worked first to promote keyworking within the English government initiatives of the new decade, and now promotes work to help families of disabled children, young people and adults with their sleep deprivation issues. (www.handseltrust.org)

Cartoon © Martina Jirankova-Limbrick – first published in PNR magazine