Disabilities
Pathways and perspectives

Iriss

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CONTENTS

1. About this resource

This is a co-produced resource which is based upon an organised series of discussions on the theme of 'disabilities' in personal and professional life. Fourteen co-authors, including two couples, shared aspects of their own pathways and developing perspectives on disabilities, in a wide variety of contexts and countries including England, Scotland, Ukraine, Greece and Brazil. The aim is to stimulate and support critical reflection on dimensions of practice and care.

Co-authors each reflect in their own way and emphasise what is important to them. Bringing their pathways and perspectives together may prompt readers to consider values and skills that bridge academic and practice education in social work. In this resource, these questions and considerations arise through experiences of and engagement with 'disabilities'.

This resource is in three main sections:

- **Section 1** outlines key themes, the origin of the idea, anticipated impact, use and audience, and the approach used to develop this resource
- **Section 2** presents the twelve stories
- **Section 3** discusses how this resource can be used
- **Annex 1** and **2** provide reflections from co-authors and critical friends

CROSS-CUTTING THEMES

Themes emerging from the stories cluster around four key areas:

- **Awareness of diverse pathways and meanings of disability**. This means recognising the whole person and valuing how experiences, relationships, values and beliefs, shape individual and shared journeys.

- **Awareness of personal, relational, social and structural barriers affecting and accentuating experiences of disability**. This arises from disrespectful labelling, gaps in community support, and the challenges of navigating dependency, boundaries, and personal vulnerabilities.

- **Attitudes such as openness of heart and mind in practice, care and working relationships**. This requires sensitive listening, lifelong learning, and humility, fostering joy and mutual growth in relationships and work.

- **Various dimensions of leadership (personal, collaborative and systemic)**. Leadership in action combines compassion with practical action to advocate, innovate, and address systemic challenges with persistence and creativity.

THE IDEA

When practitioners, parents and carers participate in group teaching, their realities can bring motivational spirit and insight to the learning process. Stories are often held in mind as reference points. Their personal accounts bring colour and depth to enhancing critical understanding of each context.

As students and newly qualified practitioners navigate each field of practice, they develop a deeper awareness of their own perspectives, power, assumptions, intuitions, and blind spots. Cultivating curiosity and an appreciation for diverse ways of seeing and understanding is an ongoing process and an essential foundation for effective practice. Sensitivity to others' experiences and the ability to listen deeply, beyond words, are integral to the thoughtful and intentional 'use of self.'

The term *'use of self'* is used here to refer to the way we connect, listen, communicate, and collaborate, with others in learning process and working practice. While the way we engage varies across different cultural and work contexts and roles, ethical and effective use of self in social work education and practice includes:

- Engaging with honesty and integrity
- Listening with care and respect to the experience and perspective of others.
- Developing self-awareness
- Critical reflection on the influence and impact of our values, beliefs, culture, experience, relationships, and actions
- Working with care for ourselves and others, within personal and professional boundaries

IMPACT, USE AND AUDIENCE

The hope is that this synthesis can be used as a resource for supporting individual and group reflection with students and practitioners. This resource has a wide audience including those in social work education, practice, research, and policy.

The resource might be used flexibly and selectively to bridge classroom and practice experience. However, the application is potentially broader, in team training and development, in the way we seek feedback, participation and engage in co-production, whether that be in development of practice, policy or research.

We also acknowledge that, due to the depth and complexity of the material, engaging with this resource in its entirety may feel demanding for some readers. With this in mind, we encourage flexible, creative, and accessible approaches to using the resource. The stories, originally shared through spoken word, may be particularly powerful when read aloud – in pairs, small

groups, or facilitated sessions. This can bring the narratives to life and make them more engaging and relatable, especially in classroom, training, or reflective spaces. Stepping into the shoes of the co-authors, can encourage empathy, challenge assumptions, and create space for meaningful reflection.

Other accessible approaches might include:

- Using visual summaries or story maps.
- Breaking stories into shorter segments for discussion over time.
- Providing alternative formats (e.g., large print, plain text or easy read).
- Encouraging personal reflection or journalling in response to a single story.

These methods can help a wider range of people connect with the stories in ways that suit different learning styles and needs. Overall the aim of the resource is to provoke a critical awareness of personal and professional attitudes and actions.

Critical friends

Eight critical friends provided perspectives on the draft. They praised the stories as insightful, moving, and thought-provoking, offering both personal and professional perspectives on disability across cultures and countries. They highlighted the humanity, warmth, and real-life relevance of the stories, contrasting them with more academic and 'dry' resources in social work. One described 'a relief to find such wisdom' and another, that the stories 'left me feeling humbled and in awe'. Other points included:

- The first-hand narratives and collaborative approach make the material engaging for practitioners, students, and policymakers
- The resource challenges existing perceptions and practices, emphasising the struggles for inclusion and the importance of belonging, being known, and being accepted

- Several critical friends express their intention to use the resource in teaching, training, and professional development
- The interdisciplinary and international perspectives enrich the discussion, offering a broad and comparative understanding of disability
- The resource is a call to action for more inclusive policies, professional humility, and meaningful engagement with disabled individuals and their families
- Social work education and practice must go beyond technical skills and emphasise critical reflection, personal engagement, and the breaking down of systemic barriers

Reflections from critical friends can be found in Annex 2.

APPROACH

This section outlines the approach taken to developing the resource.

Source

The sources of these synthesis are conversations which took the form of lightly guided discussions, rather than 'semi-structured interviews' ('light' in the sense that the co-ordinator attempted not to intrude, control or interpret). Co-authors had a shared understanding of the purpose of the exercise and each person plotted their own course and set their own boundaries. The co-ordinator offered few prompts and only actively participated in the discussion when it was necessary to check, acknowledge, or focus on points made during the open, unstructured conversation.

Positioning

Participants are co-authors and are not representing any institution or agency. Their understanding, permission and power of veto on any of their own shared material has been a key principle in conduct of the process and co-production of the resource.
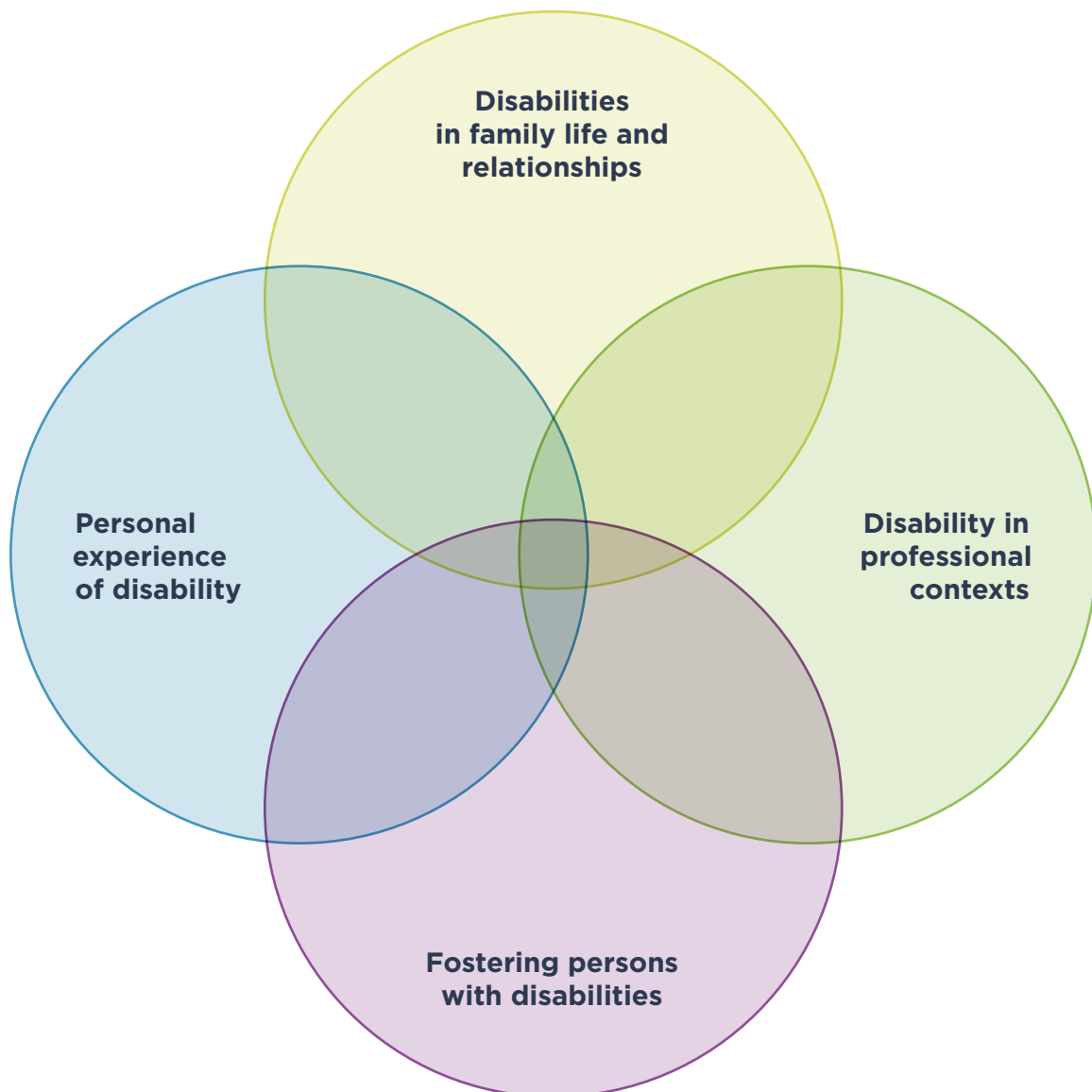
Participation and pre-selection

Individuals were purposefully selected because of the known range of their experience as relevant to 'disability' and previously evidenced skills in sharing personal learning.

The contexts and sources

Co-author reflections are summarised in figure 1 (below). These symbolise dynamic intersection between personal and family experience, life and space, and engagement with disability in diverse professional contexts in the UK, Ukraine and Greece.

Disabilities in family life and relationships

Personal experience of disability

Disability in professional contexts

Fostering persons with disabilities

Figure 1. Interactive contexts for reflection on disability

Boundaries

Each co-author brings their own perspective on the meaning of 'disabilities' to the discussion. The line between personal and professional can vary, change over time, and needs to be considered carefully. These boundaries are not always clear cut. While some personal matters should remain private, certain private experiences, beliefs, and vulnerabilities can still influence work and care-giving relationships, even if they are not directly shared.

The style and language

Language in this resource fits the terms used by co-authors. For example, the term 'intellectual disabilities' was preferred and meaningful to Ukrainian co-authors (rather than 'learning disabilities' , which is often used by UK based contributors). The term 'disabled person' might be used in line with policy associated with a 'social model of disability'. 'Person with disability/disabilities' is used more frequently by co-authors here. The UN Convention on Rights of the Child uses both terms and the UN Convention on Persons with Disabilities only once refers to 'disabled persons'.

The style and form here is non-academic. Citations and references are only used where they emerged in conversation. Thematic observations derive from contributors' reflections in the stages listed below. The aim has been to respect their interpretation and minimise weighting that might bubble up from background analysis of the coordinator.

STEPS IN COLLABORATION AND CO-PRODUCTION

This section outlines the process underpinning the development of this resource.

Gathering and summarising pathways and perspectives

The co-ordinator and co-authors collaborated to share reflections and edits on the stories. This occurred through individual discussion and group discussion.

Individual reflection on process

The co-ordinator also offered co-authors individual meetings to explore their impressions and learning from the process and they had the opportunity to edit the summary of these discussions. These can be found in Annex 1.

Critical friends

A separate small group of people with relevant expertise read a draft of 'pathways and perspectives' and were given the opportunity to comment on their impressions and learning. These can be found in the Annex 2.

Coordination

The co-ordinator of this process is a social worker and lecturer in social work; with 40 years relevant experience in social work and social care, in a range of community and institutional, government and non-government settings. Additionally, the co-ordinator has a special interest in the ways social work can support challenging life transitions through support for carers and families including facilitation of family group decision making.

2.Stories: pathways and perspectives

This section presents twelve stories. Each starts with a short introduction about the author(s). Styles and language vary as they are from different authors, contexts and countries. We have purposely not changed them to preserve their differences. They can be read in any order.

Tom Frank

Tom has 50 years of experience in social work, moving from England to Scotland early in his career and shifting from a focus on direct practice to professional development of social workers and students. Retiring from social work, Tom sustained his interests in counselling and advocacy; and in exploring the consequences of perceptions of disability and mental health. Tom was born with cerebral palsy. In this conversation he shared some critical reflections on his own professional motivations, assumptions and identity. Some of his observations triggered by 'disability related' matters have generic resonance within social work.

I was born to a middle-class family. My parents were advised to let me 'find my own way'. They did not make specialised or different provisions. Teachers adopted a similar style of encouragement. I did not see myself as 'disabled' and became highly articulate. This may have played a part in acceptance and popularity in school and later in professional training. I was politically left wing and critical of stark social inequalities in a capitalist economy. Professional motivation was underpinned by an urge to challenge structural and systemic injustices. Social work is political but I was polarised in my views, young and naïve.

I was sponsored to do my social work training (by the local authority). The senior social worker who interviewed me posed a question that shocked and disturbed me. He asked, '*How do you think clients will view your disabilities?*' I was upset, feeling that should not, in principle, be a consideration. I soon realised the direct, challenging value of the question, going far beyond the appearance of disability. Social work is not a series of

procedures for work with types of people. Clients are people with whom we are in professional interaction. Not 'types' of person categorised by types or degrees of problem. Professional relationships are influenced by the way we present, are perceived, and understood. What is assumed about us? How does this influence shared understanding and working relationship?

I was ably 'finding my way.' I felt able, accepted and liked, an able-bodied person among the able-bodied. Paradoxically, my self-awareness about aspects of my own disabilities and recognition of my reactions to the impairments of others were dimmed. It took me years to recognise where my actions were constrained by my own discomfort and avoidance. I recall an early career visit to a 15 year old with cerebral palsy. I now see my approach as bureaucratic and procedural, quite tersely signposting the family to a daycare resource. I recall the interaction as in a nightmare in which I was distancing myself from the person and any form of personal engagement. It was as if I was clinging to the structural and procedural issues.

This makes me realistic about how difficult it is to support the professional development of workers who are embedded in a rigid typology of service approaches, where social work is reduced to treatment, categorical entitlements, and social administration.

In my early social work days I began to respect those colleagues, some of whom had contrasting political stances, who somehow managed to find a balance through a comprehensive understanding of the law, administrative systems, their opportunities and flaws, and yet could keep a personal focus on individuals and their family and community relationships.

I found it very difficult to keep the balance between the political and the personal because I felt safer to stick to a political and structural approach. The more anxious I got, the less I was able to hear. I worked with a woman

with cerebral palsy, I struggled to understand what she was trying to say with her communication board and the relationship went flat. I began to realise that I needed to put more effort into learning about her communication. I also realised that we needed a special form of training (not 'specialist' training).

By this I mean that we needed to develop confidence and determination in finding and learning ways to communicate, including through advocacy. I respect colleagues whose professional communication always includes emotional sensitivity and recognition.

I also remember working with an occupational therapist who blended her practical training with relationship skills. I felt envious of training that combined these elements. Sometimes practitioners talk in very rigid terms about professional boundaries in practitioner or caring relationship, for example avoiding the sharing of any personal information or feeling and I am alarmed about (the stark impersonality of) that attitude. At the same time I recognise that the boundaries between professional, personal and private matters are complex.

I remember in those early days reading Bill Jordan (1970)[1] on "Client-worker transactions" and Mike Simpkin (1979)[2] on working with people "trapped" in welfare systems. They recognised the challenge of finding this balance. I believe social workers have a key role in helping people navigate the bridges and barriers in the social and structural landscape.

The potential contribution of social work is personal and structural, relational and practical. I recall a colleague who pioneered the use of 'direct payments' by local authorities to people with disabilities and their families. This was a step change in enabling choice, control and self-determination

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1   Jordan, B (1970) Client Worker Transactions. Routledge.
2   Simpkin (1979) Trapped within social welfare. MacMillan/Red Globe Press.

within support and care arrangements, twenty years in advance of 'self-directed support' legislation and policy in Scotland.[3]

Critical reflection on the way we engage in each context is essential in each role and in the course of each interaction and relationship.

Towards the end of my career, I became interested in how to support practitioners better within complex and stressed administrative structures and became involved in proposing social work supervision which integrated critical reflection on our assumptions, ethical judgements, and the influence of anxiety and emotional dynamics both in organisational cultures and in professional and caring relationships.

My experience has been that these elements can influence teamwork, practice and decision making and yet they too rarely receive supervisory consideration. This dimension of support is likely to be necessary in any context where the complexity and interaction of risks and needs can seem overwhelming, leaving practitioners wondering where to start and when to stop. Supervisory support in these dimensions is essential to sustain practice which combined practical help in relationship with optimism and a determination to support every 'client' to access opportunities and realise their potential.

I recently co-edited a biography of Jimmy McIntosh (Fox 2022)[4], who was a nationally honoured campaigner for equality and disability rights in Scotland. His story is both shocking and inspirational. He lived for most of his life in a sequence of abusive, discriminatory and neglectful forms of institutional care, including 40 years in Gogarburn Hospital outside Edinburgh. Jimmy successfully fought for voting rights for patients, fighting cuts in social services and setting up advocacy services. The extraordinary

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3   Scottish Government (2024) Social care - self-directed support: framework of standards: May 2024.
4   Fox, L (2022) 'As Long as We've Got a Voice': The Life of Jimmy McIntosh. Thirsty Books.

optimism and endurance of Jimmy was inspirational. Despite bullying, controlling and vindictive community harassment, Jimmy remembered those instances of kindness and 'normal' opportunities for relationship and independence that gave life humour, hope and meaning.[5]

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5   Scottish Documentary Institute (2011) 'Jimmy'. Accessed on 6.11.24
     at **https://www.scottishdocinstitute.com/films/jimmy/**

Dr Maura Daly & Professor Mark Smith

Maura has forty years of social work experience in residential child care, local authority and non-government practice and management of child and family services. She is a lecturer on social work with research interests that include social work identity and support of newly qualified social workers.

Mark is similarly experienced in social work. When he left practice he was a manager of secure accommodation services for children who are at risk of harm or of harming others. He has since been subject area lead for social work at Universities of Edinburgh and Dundee and his academic interests include social pedagogy, critical appreciation of residential child care, the nature of 'care', and the evolution of social work in a 'changing Scotland'.

Thirty years ago, Maura and Mark (who are married and have three adult children) first offered respite family care for a five year old girl ('Dawn'). She had a rare genetic condition which affected her growth, emotions and control of appetite. When Dawn's family moved to another area they began (and have never completely stopped) providing flexible respite care for a two year old boy ('Duncan', now 25 years old), whose physical and learning disabilities severely limited his mobility, speech and comprehension. The couple also have many years experience of care and support for unaccompanied (asylum seeking) young people.

Maura: When we started providing respite care, we had many years of residential child care experience behind us. Since childhood I had been involved in voluntary community activities so it felt like a natural

development. We were not long married and our first child was two. We could make time to sustain a commitment and give exhausted parents a break by welcoming these children on planned regular weekends. Later, when we had three of our own children, social workers did not think we could or should offer care for another child with disabilities. We were in the strange situation of having to persuade them when we were assessed and prepared in groups, in order to be approved by a panel.

Mark: There may have been a faith element in motivation to foster. I followed Maura's enthusiasm at the beginning. I did not pretend to be knowledgeable 'about disability' and I was not sure how confident I would feel. Confidence and trust evolves in each situation between all involved.

Mark: It is hard to make comparisons with other forms of work but I feel that these long term relationships through fostering have felt like a deep contribution between us for (the children fostered) and their parents over the years. This has been significant also for us and for our children who from early childhood have grown up accepting and enjoying the individual nature and difference of each child staying with us, playing, having fun, finding ways to laugh and joke, welcoming them to share time with friends.

Maura: 'Dawn' was not often enthusiastic about anything but you could tell when she felt comfortable and safe and that she wanted to come with us. 'Duncan' on the other hand has such a sunny disposition, loves company, finds watching people kick footballs in the air or jumping into water hilarious. But he is very sensitive to loud noises, and gives me a grumpy look if I scold one of my own children. He is very close to them and they love him.

Mark: I feel that what we have experienced through care has also been contributory to our teaching, academic interests and work relationships. Of course we are interested in inclusion and supporting potential but there are

some aspects of dependency and need that we have to accept as a steady, long term element in some 'care' relationships.

Maura: We have had to be flexible, sometimes unexpectedly. We fitted in with the timings that Duncan's mother preferred. Duncan came to us when his parents, for the first time in his life, took a holiday together. When his mum was diagnosed with the final stages of cancer, we adapted during the last months of her life and after her death we had Duncan full time for a while, to enable his father to cope and to work.

Mark: Our youngest son, like all our children, may have learned much in relationship with Duncan. He has been extremely attuned to the communication and needs of adults with disabilities and for some years was motivated to work with a non-government organisation that specialised in support for people with learning disabilities. With one young adult he has been asked by the family to sustain ongoing support and this relationship has continued for 3-4 years and seems significant to both. As carers and as a family it is not always possible to be rigid about professional boundaries but I believe we are all extremely careful and try to be 'tuned in' to the effect of our own actions on those we have cared for. This is a dynamic, requiring a constant awareness.

Maura: When Duncan lost his mother it was very difficult to know exactly how this affected him. We tried to help him recognise when his mother was ill and prepare him for her death; he stayed with us while she was in hospital and came to the funeral. He loved his mum dearly. We believed a sudden and final disappearance would be more difficult than some sense of what had happened. We do not know. He had a lot of extra attention around this time and he is very preoccupied and sensitive to what is happening in his immediate orbit but not to what is happening out of sight. As a young adult, Duncan and his father urgently needed help exploring

options for his longer term home base. Acting beyond my role as a carer we needed to offer a transitional bridge, helping family and social services find an arrangement in a flat with two other young adults and with carers; and meaningful routine of daytime activities through a local third sector organisation specialising in developmental and enjoyable activities geared to each person's abilities. Duncan seems very happy at this stage in his transitions to adult life and is able to keep all his significant connections.

Raisa Kravchenko

Raisa is one of the first group of social workers to qualify in Ukraine 30 years ago. She is an ex-director president of the VGO Coalition, a network of 118 Ukrainian local non-governmental organisations for persons with 'intellectual disabilities' generating support, advice and advocacy for about 14,000 families from all the regions of Ukraine (Kottasova & Kesaiva 2023).[6] Living just outside Kyiv, in 1996 she also founded 'Djerela', a local Disabled Persons Organisation supporting around 180 such families and associated carers through respite, activities, community support and online connections. On a local and national basis Raisa has contributed to the development and facilitation of training for professionals and students; and especially since the full-scale invasion of Ukraine in 2022 she has contributed through travel, writing and presentations to international awareness of the impact of the war on people with disabilities and their families in Ukraine and in flight.[7] Raisa related glimpses of her perspective, at the heart of which is her life experiences as mother of her 40 year old son, who has intellectual disabilities and now lives nearby in a group home, her awareness of the impact of disabilities on her own health, and on the caring responsibilities of the majority of her closest colleagues and friends.

Colleagues and families in Kyiv are sleepless every second night these days. The sirens go. They have to go to the shelter. Some days the shelters are full of hundreds of children. Teachers try to run classes in there. Imagine.

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6 Kottasova I, Kessaiva Y (2023) Impossible Choices. Accessed on 26 September 2024 at Ukrainians with disabilities and their families struggle as war makes life even harder (cnn.com). CNN 28.3.23.

7 Raisa has co-authored a chapter in an internationally edited book (forthcoming, Springer) on social work with people with disabilities in the context of the war in Ukraine. She substantially contributed material to Zaviršek, D., Cox, J. Navigating Minefields: Social Work with People with Disabilities in the Context of War. Journal of Human Rights & Social Work (2024). **https://doi.org/10.1007/s41134-024-00329-9**

The threat of power cuts is always there. People and organisations must help each other in practical ways. Recently the generator in my son's group home broke. We (the NGO Djerala) had a spare and gave it to them.

You have to realise that besides the death and the trauma, there is a huge gap in human as well as material resource. Six million Ukrainians have fled overseas since February 2022 and perhaps 5.8 million remain abroad. A greater number are displaced in country. Two years ago many people were interested in a profession working with people with disabilities. As you know we developed a comprehensive training package to enable them to enter this work; and 350 young people completed the whole course. But now the situation is different. So many have been absorbed by the military and other occupations in this new context.

Just now, twenty of us, leaders of NGOs, meet twice a month. We have found that the essential driver for those who hold to this work is a live connection to a brother or sister or someone close who is affected by such disabilities. We ask those coming forward to think carefully about what they are considering. In some ways they are going through a door into a different world. This is an opportunity, beyond 'skills', to think deeply about life's values, about all of life and also to feel hope because despite so many challenges, people with intellectual disabilities each have so many positive characteristics that it is a great pleasure to spend time with them.

However, if you come into this work you must be prepared for ethical dilemmas .You may have personal and professional ethics. We also have national standards for each service. One such standard in Ukraine states that practitioners are responsible for equal access to services. But, especially in wartime, fair and equal access is impossible. The individual or organisation cannot be held liable for systemic shortages, gaps and failures. I myself may have to refuse service because we can only provide, with some difficulty, for our

membership and although I promote our services, I have to prioritise and turn many who need services away. Going against the grain like this is a constant tension for us and creates feelings of injustice for those needing services.

It is complicated. It is so difficult to sustain funding. Most organisations just have to generate their own. We did an analysis of 7 services for people with intellectual disabilities and found that money they raised for key projects is usually time limited. When the money stops the project fails.

For example we raise money to survive and develop respite services, spending up to 20-30% on publicity for advocacy and awareness raising. Many families come forward. In these times some are completely isolated. But we are limited in what we can do. We have to turn many away.

Yes, listening is vital. But I have at times I have experienced the opposite, from those with power and authority. So often egocentricity determines whether a person will listen and what a person will hear, according to their own goals.

I can remember the professional skill and mastery of disrespect that was displayed to me by one senior official visiting our services who deliberately 'blanked me', my communication and contribution, walking straight past me without acknowledgement in a small corridor.

Even now my son helps me to listen. It is not always easy. I worry about him roaming about during these times. It is dangerous. Soldiers sharply said so. I told them that you might as well try to stop the wind blowing or the sun rising. It is what he needs to do to manage his feelings. He needs to wander. If I am strict with him, he is now able to tell me that at his age he is responsible to choose what he does, like all adults. That he has a right to roam.

Maybe 45% of individuals with intellectual disabilities that we know about have very challenging behaviour. In our experience, much of this is to do with the absence of opportunities for employment and fulfilling activity.

Gaps and failures are again exaggerated by the war. Being occupied is important but this is deeper. It is about belonging, acceptance, relationships, livelihood. Many young people with intellectual disabilities fled with carers and parents abroad and many returned (they were simply 'warehoused' and opportunities for occupation were rarely provided). Carers can also feel very isolated, anxious and depressed in these transitions and need support.

I have encouraged the development of online support for carers and people with intellectual disabilities via zoom meetings both in Ukraine and overseas (for example in Denmark). I am really interested in the aspects of occupational therapy that considered holistic assessment of needs, material assistance, skills development for living and occupation and associated adaptations to the environment. I see the need for development of training in Ukraine which integrates personal and structural dimensions of transition and promotes individual rights and wellbeing. I am concerned about attitudes to people with profound intellectual disabilities that ignore their needs and rights to relationship, their sexual development, as part of support for their health and understanding.

I have never heard of support for a person with intellectual disabilities to get married. Of course, relationships including the potential for sexual relationship are a basic part in every person's development in some way. It is not surprising if the ignoring of this plays a part in behaviour we find challenging.

As a practitioner and as a carer, especially in war we have to be aware of the situation, for example when something changes abruptly. We may be aware of our own reactions but we have to be disciplined and contain our own feelings in order to focus on what needs to be done.

We are directly involved in the support of 50 people working in eight services and we have a lot of student involvement. At any time and especially now, we try to promote a warm and accepting, friendly,

informal atmosphere. This is essential to sustain the will to continue when we do not know when the current situation will end. It is essential to sustain purpose, confidence, hope and belonging. I remember someone who had to leave us recently for a job that paid more money and she spoke to me last week about missing the sense of acceptance here.

I value reliability. By this I mean when I know someone will always try to do his or her best and will try to act in a trusting and trustworthy way. At the same time I feel in my team we all need to respect each other's situation and be flexible. Most of us have direct caring responsibilities and our own health issues. Working together around these unavoidable constraints is essential for an effective team.

Theano Kallinikaki

Theano is Emeritus Professor of Social Work at Democritus University of Thrace, Greece, with 50 years experience in social work, social policy, social work education and research. Theano has had a formative influence on professional social work education in Greece and beyond, with a wide range of significant collaborations across Europe. She has had special interests in fields including child and adolescent mental health, child protection, foster care, social work with asylum seekers and refugees and anti-discriminatory practice, including but not limited to policies and practice with people with disabilities. She has personal experience of a physical disability.

A combination of memories from early childhood have remained sharp for me. My uncle lost both legs above the knee during World War 2. I loved him and we were especially close because he had no children. There were many war-wounded where I lived in Crete. It was a small village.

Our neighbour's little boy Stergios would come every day, winter or summer, snow or shine and sit beside my grandmother, asking for the same story, every day. I was curious but just accepted, just as my granny recognised and the community accepted, that was what he needed. He had no watch. But his ritual became part of the family clock. Later I understood that he was autistic. He needed the repetitive security of time, story and familiar person alongside. I learned intuitively about the need to give each person time. From a very young age I would tend to sit next to persons who were obviously disabled. I might ask how I could help.

My personal experience of disability may have strengthened my sensitivity to the experience of others – although I never made this association as a child.

My left arm and shoulder was severely damaged in childbirth. The secondary harms of poor remedial treatment accentuated the damage, which has been lasting. I was left out on the edge of many activities normal to childhood.

As a young girl, I felt the injury caused to me as a baby at the time of delivery not only through my own feelings, understanding and personal impact on me, but also through the directions, feelings and understanding of those around me. For example, my loving and God-fearing mother and grandmother prayed for healing and delivery via their own prayers and ritual penance. I felt responsibility, almost like guilt, for causing them such stress in their hearts and bodies. They told me that I would only recover if I was good. A doctor caused my injury in childbirth. Ironically, medical ignorance compounded the damage. I was forbidden from my involvement in school and sport activities with my friends. My arm was bound in a sling for years. Remedial physical therapy was not available. My father provided a balancing calmness and rationality. He encouraged me to read and learn languages. I had to leave the village to attend high school at age 12. I think I left with the seeds of determination. My loving family had expectations for me. I would work hard. But already I doubted God would resolve unfairness and fear. As I grew through adolescence I became curious about ways to contribute to social change. These formative memories are all deeply connected. Any person for whom 'disability' has significant personal meaning will have their own interconnecting stories. This sort of contextual understanding is vital.

I have been critical of social policy in Greece. It is a strictly medical approach. People are categorised and entitled to categories of welfare benefit according to categories of functional impairment. For many years those in the most severe category were not *allowed* to work. There was some incentive to be labelled in order that individuals, parents and institutions received state benefits in respect of individuals. We have to ask how these forms of rewarded categories may also disempower and constrict individual development.

I have always been concerned about the impact of this structure on individual rights and potentials. I have always taught students to be wary of labelling and associated assumptions about categories of individuals. I teach the 'social model' of disability, and am wary of the word 'disabled' if it is ever used to typify individuals.

Few students are aware of the ghettoisation and institutionalisation of disabled people in Greece; of the lack of inclusive education; and lack of employment opportunities beyond special workshops. They must be critically aware of this context.

I have usually avoided speaking of my own experience of disability to students, unless there was a special instance where their questions were about my experience. However, in developing and directing courses on social work with persons with disability, I have encouraged curiosity, recognition and respect for the daily experiences of each person.

For example, class groups were tasked to spend several days attempting to tune in to the likely challenges for people experiencing a range of different forms of impairment, both physical and in relation to intellectual capacity and mental health.

And then fourth year students were systematically linked person to person as mentors for first year students, where young people living away from home for the first time may also be struggling to navigate this due to diverse aspects of their own identity, including disabilities, ethnicity, language and cultural difference. The mentoring approach was valued by both first and fourth year students because, through practice, it promoted shared understanding and inclusive relationships and related skills.

Also at the University we have an established partnership with a large institution for children with disabilities. We have open days when children

come to the campus and students are paired with these visitors to welcome, guide, support and eat with them during their visit.

Foster care has been slow to develop in Greece and children without parental care or removed from parental care most often went to institutions. The Greek Orthodox Church is a big provider of institutional care, for children and adults, including persons with disabilities. But these places are very closed worlds, a private social and religious phenomenon in many communities about which public authorities have very little data. It is true that a small number of disabled children have been cared for in long term foster care. Although alternative care of children through approved, supervised and funded foster care was introduced by law in 1996, it is still in developmental stages.

It is true that many people with disabilities are more aware of their rights and some NGOs and grassroots organisations play a valuable role in advocacy. But individuals do not have the power or money to challenge non-implementation of rights through the law.

Since the mid 1980's, I have been involved in analysis and policy development in relation to de-institutionalisation of large institutions for persons with mental disorders and intellectual disabilities. One significant factor in relation to slow progress was the dependence of whole communities for their employment as health, care and maintenance and administrative roles associated with these large institutions. We need a sustained and adequately funded whole system policy and programme that recognises the ecology of institutionalisation.

It is also true that many disabled people in the community have been closely protected by their caring parents throughout life and they have had little practice in guided self-direction, even when they have the capacity to learn to find their own way around within the local community. This can constrict individual development, relationships and can leave them more vulnerable when parents are no longer able to care.

I believe that it is necessary but not enough to have a coherent and funded policy. Transitions from institutions for people who have spent many years within them are complex and support has to be individually suitable. Stages and solutions require personalised and sustained support. At the same time we have to think in terms of the needs of inter-related communities within and outside the institutions.

Over the years I may have become more radically opposed to labelling of individuals. But I was reassured when, last week, some students whom I taught ten years ago related how some messages had 'stuck'. For example, I always suggested that any feelings of 'empathy' are just a beginning. Everyone is unique and we must have the humility to accept that we can never define a person and never know all about a person's experience.

In a second conversation, one week later: For me there have been multiple dimensions of context, which influenced my development and perception of disability. As a child, I lived in a small Cretan village. Alongside sharp memories of sea and rock, donkeys and olives, my family and neighbours were deeply traumatised by recent memories of German slaughter of civilians and also by the brutalities, bitterness and fear associated with stages of civil war.

Kateryna Buchko

Kateryna is a lecturer in pedagogy and social work at the Ukrainian Catholic University (Lviv, Ukraine) and a visiting research fellow at University of Stirling. She has many years of direct work experience with children affected by autism and in support of their families in Ukraine. Past research interests have included the example of children affected by autism feeling ' together, yet finally alone' children, in schools intended to be inclusive. Current research interests include the experience and integration of Ukrainians displaced across borders by Russia's full scale invasion; and the experience of children and the humanitarian practitioners supporting them in front line areas in Ukraine.

Preparation is everything. To help others or to teach we have to be self-aware of our strengths and fragilities, our limitations. This is never ending. Self-care is part of this process. Thinking ahead is part of what helps me to be helpful. There will always be things I cannot anticipate. But I do try to imagine how I will react in new situations.

I have never assumed that a disabled person is 'traumatised' or 'broken', needing somehow to be mended. I see each person as a *full* person, even when they have severe impairments. This perspective also comes naturally as a belief, strengthened by faith.

I struggle with the general phrasing, 'being disabled'. I also feel some tension about the term 'inclusion' when it implies a failure to comprehensively include everyone. I believe in striving for inclusive and participative opportunities wherever there are additional barriers. But I think the concept, though it might seem out of reach at first, is not an illusion, like the kingdom of heaven – it represents a real and meaningful hope.

'*Ausschließlich gemeinsam, schließlich allein*' ('Exclusively together, finally alone') was the title for my doctoral research, considering inclusion in school, the pathways of children affected by autism and the attitudes around them. That study left me with more questions than when I started! But I do believe that inclusion involves respect for difference … and acceptance. There remains a question for me about how, in each context, children and adults respond to obvious differences. In reality, how much difference do children and adults 'accept' or 'bear'. Perhaps we need to recognise the need for an attitude of 'radical acceptance.'

When I started working with children with autism in Lviv, knowledge of the spectrum in Ukraine was low. My theoretical knowledge was very low. It was like going into a dark room. That was overwhelming at first. I learned gradually from each child and each family. These children were severely affected. I had to discover what each child could tolerate from me.

My initial general assumptions about what children need were not useful. I started at year zero. Step by step, I learned from what they were showing me about what they could accept in contact from me, by their reactions. I also found how some children needed and wanted social contact even though they sometimes seemed to push it away. Each child taught me about the boundaries between us.

Parents with whom I worked all felt very isolated. The NGO for which I was working was founded by a parent of a child with autism. It provided a significant and sometimes the only external resource for many parents for 20 years. Beyond support for children and families, we invited specialists and therapists from overseas to contribute. I used to translate and facilitate these seminars and meetings; and contribute to the development of public information in various forms. A wider network of expertise has begun to develop in Ukraine. The topic of autism is no longer niche and exclusive.

We used to describe these children and their families as 'invisible citizens. That was their experience. It was not difficult to work together because they had for so long felt alone and rejected. So they were grateful to feel there was someone alongside who respected them and realised how much they love their children and want the best for them.

Working together was about bridging to and integrating resources. Help related to their practical needs day by day... such as agreeing physical and sensory exercises to do with their child at home... and thinking through what would be needed in future. This would mean continued hard work... there is no magic treatment.

In many situations I was motivated because I could see children and families suffering together. I am careful not to convey a sense of pity. This implies looking down somehow, from a distance. However, a spirit of compassion is motivating and strengthens learning. Aspects of my own childhood strengthen sensitivity to individuals that may feel alone or unheard or different.

With some families I have retained contact over many years. I can remember feeling some shock to see a young adult that I remember as a small child. He remains profoundly affected by autism, dependent on his parents in many ways, and unable to speak. I am always happy to see them and reconnect. At the same time I am aware of a mixture of feelings. Almost embarrassment. I was anxious that the family may have sensed this. I had somehow expected he would have 'developed out of' his condition. Was I feeling we had 'failed' to help effectively?

I recognise times when the protective qualities in parental care can also be limiting for young people with disabilities. I can try to see their perspective and try to be alongside in sharing their child's hopes and possible pathways, looking ahead. The protective dynamic is very powerful and it is very difficult to get it right when talking through alternative perspectives.

There can be a blindness in judging success by visible change. It is possible to overlook vital but less definable joys and meaningful activities, sustained over long periods and times of stress. Success includes the distinctive experience for each person of belonging, being known, being accepted. In and out of work, in each situation, the way significant relationships are lived often seems asymmetrical. They are rarely perfectly balanced in give and take, or in the way love is felt, given and received.

Tracey Francis

Tracey is a policy and development worker for a non-government organisation. She co-facilitates a national network which promotes partnership between parents, practitioners, carers and policy makers in support of disabled children's transitions into adult years and adult services. Tracey is the parent of a young autistic woman. The insights Tracey offers combine learning from intense cycles of family experience, from the bridges and barriers to effective support sought from outside the family, through her own advisory, advocacy and policy roles, and from her own research about how such transitions for young people affected by autism and their families are experienced in four European countries.

As a parent, (when I have sought professional services for my daughter), again and again I have been made to feel as though I am not a significant part of the picture. I have yet to meet a parent who has not experienced this feeling of being 'sidelined'.

Parents normally prioritise the wellbeing of their children. Most parents are constantly involved with their disabled children's care in ways that professionals too rarely respect, explore, understand or support.

I/we often felt alone. There was no one out there when I was most afraid for my daughter. I have listened to many parents who share the experience of isolation.

I did not have time to step back and process my own feelings and thoughts, or recognise the impact of caring on my own mental health. I sometimes felt there was very little left of me.

I have had to adapt and change. I am now persistent in fighting for what is needed. When I hear professional criticism of parents who have sounded confrontational, I would encourage services to consider what support these parents should have had.

To anyone who supports young people and families, I would like to say: never ever underestimate the power of empathy and simply listening. No one wants to feel they are simply a problem to be solved. Bringing your humanity into a situation is the biggest gamechanger you can offer and it costs nothing. Everything starts with listening and too often this is just missing. For example, at one stage I gave up my work in order to provide essential care to my daughter. We took in a lodger to survive financially. A psychiatrist for my daughter challenged this decision. Her manner showed no empathy or practical understanding of the whole picture.

A caring and effective service is also practical. For example, a family doctor showed flexibility and immediate understanding of a young person and family 'on the edge' and helped us break a sleepless downward spiral. One school was similarly flexible and non-judgemental in attitude, working together and accepting that there were some days when it was simply impossible to get my daughter into class.

In one business support role in which I had no power to make decisions, provide practical help, or offer clinical advice, I found that simply being human, recognising and accepting the stresses being shared could be sustaining for those who spoke to me. Even when professionals cannot provide a solution, they themselves can be a resource.

In other circumstances I have found ignorance about the potentially overwhelming consequence of autism for some individuals in some contexts. For example, it was anticipated that my daughter would feel

profoundly overstimulated and threatened in an essential journey through the pressured space of an airport. It was impossible to gain any assistance to get through because she did not need and would not get into a wheelchair.

Some services designed to offer support do not appreciate the need to manage phases of beginning and ending of a supportive relationship. In a recent example, there was no warning and no planning towards 'next steps' after the service ended, at which point my adult daughter would have to achieve key tasks alone or with identified transitional help.

Although for many children with significant disabilities, leaving school is a time when plans for next steps need to be in place, when it comes to leaving college or other forms of adult training, the emotional and practical transitions needed can be even more threatening and so thinking ahead for support is necessary.

I have given evidence to two Parliamentary Committees on legislation and policy issues as they affect disabled and neurodivergent young people. In processes like this, I think that the needs and narratives of individuals do have impact and can convey real experience. However, there is a danger that listeners can depress the value of such testimony, as 'just one example'. So I believe that a combination of robust quantitative and credible qualitative research and accounts about needs and outcomes are needed to inform development of policy and legislative change.
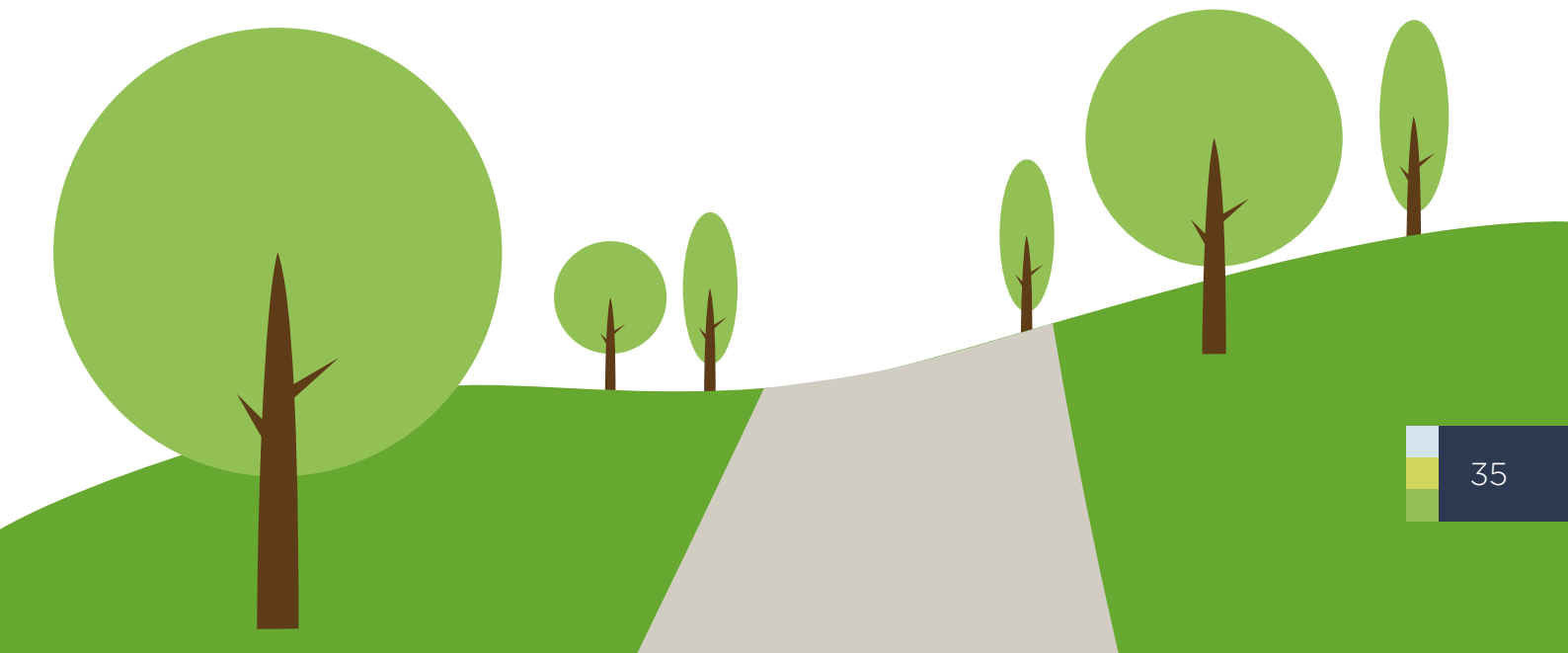
Sue & John MacFadyen

Sue and John have had long and varied careers as social workers, encompassing residential care for children, fostering and adoption, group support for children in schools with additional needs, family support, including cross-cultural practice. They are both experienced psychotherapists and supervisors of therapists; and John leads psychotherapy training. Work and life experiences merge in a conversation about an unexpected opportunity to offer a bridging foster placement for a ten year old boy – 'Daniel'. John knew about Daniel because he supported a couple who had adopted him. Early years neglect, maltreatment and witnessing of domestic abuse all appeared to be formative in the disturbed and disturbing behaviour which contributed to the breakdown of this adoption.

John: We had not planned to be foster carers. I was aware of Daniel's suffering, and of serious risks for him. I felt I could do more and was driven. It felt like a necessity for me. A loss in my close family has left me with a question I cannot resolve (what more could I have done?) So I was aware of a fear about what might happen in this new situation, if I did not extend myself. This anxiety combined with an underlying sense of a 'gap'. We have no child. This may have played a part in my own drive to offer.

Sue: Before Daniel came I had no ambition to be a foster carer. But I knew he was in a desperate situation – separated from everyone he had known. It is often true that the motivation of couples who foster is not the same or equal at the beginning. Their motivations can shift, as the fostering relationship unfolds. I backed John in his powerful motivation. Ironically, it is I who have sustained the closer relationship with Daniel and still have a lot of contact, (12 years after he moved on).

John: There were patterns in his behaviour and communication that were familiar to us from relationships with children in residential care. This helped us make sense of extreme rages.

Sue: Daniel's 'disabilities' or 'types' of difficulty were not a consideration in our motivation. But we gradually came to learn about ways in which Daniel's anxieties and communication combined autistic features with impacts from abuse, trauma and disrupted close relationships. It is always difficult to separate these strands out and every person is different in this respect. We did not assume anything about what would be possible or impossible for him. I think that it had been a significant part of my role as a social worker with foster carers to work together to 'decode' and make sense of behaviour that was distressing and exhausting, and which caused carers to feel hopeless. It can be very hard for children and carers when they open up to each other and when the fostering arrangement has to come to an end. It was certainly very hard for me. However if carers do not open up emotionally, the child's search for relationship can be lost. Many carers are not able or willing to be emotionally open.

John: The school was very committed to him and felt very warmly about him. He could be very engaging, excited and responsive, delightful in his appetite for new experiences, thoughts and feelings. I believe that sense of adults' delight in him is very important. All of those moments, often in play, were vital to his developing ability to express himself, open connections with us and later with others. However, especially at home and in public places he was very hard to refuse. He could be extremely 'manipulative'. But it was how he had learned to survive. He could be extremely loud and personally threatening whenever a boundary was set ... whenever we said, No! Perhaps I was unrealistic. I hoped that by being consistent with him and by remaining calm and quietly offering explanations he would begin to absorb some new

messages about what works and what does not work for him; and about what responses are lose-lose and win-win! When his behaviour was outrageous, I tried to maintain an attitude of curiosity about what was going on for him, what he was telling us by his behaviour, rather than retreating in shock.

Sue: He is very perceptive and seems to be able to tune in to vulnerability and uncertainty in others. Some of my family members found him alarming. He used to 'flood' us with endless and fixated demands. He still has a tendency to flood himself, going round and round in his thinking. But he is more thoughtful now and is more aware of himself. He has some sense of the impact of what he does and that makes him feel hopeless at times. He has recreated parts of his childhood in memorabilia he collects and treasures. It is as if he is still searching for fantasies he has lost.

We were able to open a channel of relationship when he was with us. But he was angry and punitive when he moved on to long term foster carers. Now he still seems to need us in a different way. He texts often. The internet is a huge danger for him because he finds it so hard to contain his own strong feelings and views. I talk with him about this. As carers we were also in constant connection with professionals, helping with plans, exploring options. So our role was structural as well as relational. And it was vital to remain balanced. It is possible to feel sidelined, diminished or blamed when things are not going well and splits can occur between professionals, carers, family members and children are affected by this. These dynamics are an unavoidable potential in social work and fostering, especially when people feel diminished, projecting blame and feeling anxiety about the future.

Ronnie Hill

Ronnie, now aged 70, draws upon experience from home life; as a social worker, senior social worker and team leader in areas of high deprivation in the west of Scotland. In mid-career he developed and directed inspection of both children's and adult services: first in Edinburgh and surrounding local authorities; and then at national level. In recent years, preceding retirement, he has been head of children's services for a local authority; and a professional adviser on children's services to Scottish Government as well as being an Associate Director for the Health and Social Care Alliance, Scotland. Ronnie and his wife Dorothy have also been short term foster carers.

One of my long term neighbourhood friends in childhood had learning disabilities. But that was not a term known to me or any of my pals. We just knew him for himself and by the things we liked and respected about him. We grew to understand the things he struggled with and saw how he managed them. Locally he was bullied, by youngsters who did not know or appreciate him. We knew him as a person. They treated him like a different type of person. The natural ease of our friendship (and the bullying) left a lasting impression and motivation – a strong sense that we have a shared (community) responsibility to tackle discrimination and injustice.

In my early social work training and career it became very obvious how multiple factors, material poverty, poverty of opportunity, poor housing, poor health, disability, all interacted and combined, especially in some neighbourhoods. We need to try to tune in to the whole ecology of people's lives in order to understand what part 'disability' plays in their needs, rights and struggles.

I have always looked for ethical and leadership qualities in colleagues and persons in supervisory roles. I have been influenced and resourced by those who do not just talk, but whose leadership is shown through noticing injustice and inequality; and then taking whatever steps they can… and seeing actions through. I have always seen leadership as a matter of collaboration and teamwork – with families, with community leaders, with primary health services, hospitals and day centres.

Leadership sometimes means enabling other people to lead, whether in a team, or in their own lives. Respect, listening and encouragement are part of this. In one of the early teams in which I was manager, one practitioner was given the time to develop knowledge and relationships relevant to local disability related services. He built a community of knowledge and channels of communication across professions for the whole team. This form of bridging made a difference at local level. I remember feeling that achieving sustained policy changes at a national level felt beyond our sphere of influence. We do what we can.

Now, in Scotland, we do have a wide range of rights-based policies, legislation, guidance and structures, all intended to reduce the disconnected, 'silo' approach to providing services for 'categories' of need. For example, the 'Getting it right for every child' policy and national practice model makes sense, especially where needs and risks are complex and coordinated planning is needed with families. But taking action to ensure a joined up approach still depends on the energy and integrity of practitioners at local level.

Structures and resources do not in themselves provide the answers. We have to provide training to ensure professions do work together. We need to be persistent and realistic. And we have to be accessible with our information and approach so that individuals with additional needs can imagine steps they might take; can work through choices they might make; have someone alongside through decision making processes in which they participate.

Information and explanation has to make sense to each person. This takes time. It may mean adapting how we communicate. It may mean there is a need for advocacy, especially but not only for those affected by, for example deafness, blindness, intellectual disabilities and communication barriers created by inconsiderate and procedural attitudes.

While it is vital that people with disabilities have a voice in the development of policies and plans that affect them, some families affected by disability are probably getting weary of research . They may be sick of being asked for their views . In this country, the core messages from families have been consistent over the last twenty years. These core messages are well represented already by advocacy groups and organisations. For example, the Association for Real Change (ARC Scotland), has co-produced, with hundreds of families, practical principles in support of young people with disabilities and their families in their diverse journeys into adult life and services.

Yes, families want to feel respected and fully involved in planning. Yes, they want to be considered as a family in which the 'holistic' needs of adults and children, carers and cared-for, are often inter-connected. Yes they want the support to be 'strengths-based', so that we help develop potential and sustain relationships and work together in a coordinated way, (for example when complex conditions and circumstances pull a range of professionals into plans). Yes they want essential support to be provided as long as necessary, rather than up to a certain age, deemed 'adulthood'. However, in practice, we have to work hard to ensure that principals do not get lost in procedures.

Sometimes we have to take extra steps and reach out to individuals and families with whom services find it hard to engage or who find it hard to access services. That takes creativity, initiative and validation by leadership when resources are short.

Effective inspection and improvement of services rarely occurs through rigidly procedural investigation and reporting. As with the work with families, inspection officers have to understand the context, build an understanding about the current situation, develop relationships through clear and reliable communication and collaborative agreement about necessary steps in the direction of improvement. That means 'following up'. Where we recognise excellence in services, foundation evidence comes from the experiences of those using the services and their families, evidence of their meaningful involvement in plans which meet their individual needs, and in how the overall service is delivered and quality assured.

Bob Fraser

Bob Fraser has worked in public health and social care services for 40 years; and has been a professional adviser to Scottish Government about children's services. He and his wife have five children all of whom have various long term additional support needs; and the couple have fostered children over 25 years, adopting a child affected by autism and other conditions. They continue to support her closely into adult family life. Bob is now Chief Executive of a non-government, national centre for integrated learning, therapy and care for children in Scotland affected by motor disorders. This often relates to impairments through acquired brain injury, complex and multiple learning disability and rare congenital and genetic disorders. Bob chairs a national interdisciplinary network for professionals involved in child protection of disabled children.

I think about each adult or child as an individual, trying to understand their presentation, experience and context, including history and how this may be impacting on their life now and potentially for the future. I may not know their exact 'diagnosis', they may not have one or they may have a number of conditions that are interacting. I encourage colleagues not to fixate on uncertainties of fact in 'assessment', rather to understand how the child or adult experiences their world. If there is a long term impairment, how can we work together to mitigate whatever the resulting difficulties may be? I believe that this attitude fits well with our equalities legislation and policies in Scotland.

We may never understand fully the ways that different conditions (including physical and mental health conditions, learning disabilities and life experiences) interact to create long term impact on day to day functioning. I try to keep an open mind and gradually come to understand the person, their family and the

pattern of the challenges in their lives. Working together, this is a process of professional judgement which is not replaced by diagnosis.

The word 'disabilities' or 'disabled' can carry stigma. I have felt this within my own family. Social attitudes affect the way we see ourselves, and how we sometimes do not recognise or accept our own long term conditions and impairments.

Listening often involves attending to everything in the child or adult's presentation – even the smallest of movements may convey a meaning for a child who is unable to speak and may not be able to use the most common forms sign, symbol or communication aid. We have had breakthroughs with some children whose slight eye movements have been a key to conveying reaction and understanding.

Positive steps in developing communication may take a lot of time and intensive work, recognising patterns and building an understanding … not only with the children but also with families. Parents are often already highly stressed by a range of demands on them. They may not have extra hours each day. Some parents have a confusion of feelings if they feel that for years, they could have recognised communications that have been so subtle.

Of course, resources and services are not equally spread and the supports available never equal need. Also, some families have very complicated multiple stresses. Poverty can severely limit options, opportunities and choices. We need to be as practical and realistic as possible with our support and plans, realising how things feel from their perspective.

Parents can have a range of feelings about their child's disabilities and this can include guilt and grieving. Professionals need to have the humanity to appreciate their world from their perspective.

Giving lists of advice on paper may be a useful back-up for some parents, and for others it is no use at all, sometimes just reminding them of what they

don't have capacity to achieve. Context is critical, parents may need the professionals to work alongside them on priorities developing capabilities to support achievement within their often changing context and capacity.

However, I have found that when we become familiar and empathise with families and their challenges, there can be a risk that we lose sight of the child's experience, even to the extent of becoming tolerant of unintentional neglect. We have to be honest and practical in working together to reduce this risk.

Some forms of dependency and support needs can shift or may fluctuate. Other care needs are very stable and long term. It may be necessary to accept the reality of the long term support needs of the child or adult, while constantly trying to understand the person's experience and preferences and so enhance quality of life. It is difficult to acknowledge this out loud, because it sounds as though it is different from promoting 'independence'.

During COVID-19, child protection meetings and planning meetings were often held online. I know from my own experience how this distanced some parents affected by disability and mental health problems. We have to recognise patterns in how families communicate and adjust our own communication. Otherwise we cannot make plans together.

By recognising a pattern in behaviour and how children and adults communicate we may be able to anticipate what is likely to happen in the context of their lives. We need to do better in looking ahead and being proactive.

I try to think about what lies behind individual or family anger or avoidance or unreliability. With children and adults, there are causes and meanings behind all behaviour, all communication.

As regards my own motivation over the years, I know I have a determination to do 'better' myself, better for others and to encourage others to do better for themselves. I am aware of trying to channel feelings of uselessness at times into

constructive action and a positive cycle. There have been moments when I have felt overwhelmed by needs and circumstances that are beyond my control. I have learned to recognise cycles and patterns for myself and step back. There are things I can positively influence. And there are many things I cannot control.

I have never felt completely alone in this. There have always been a few people whom I can talk to who understand. Most of all, partnership and all the balancing qualities and experience of my wife make it possible to continue to face challenges positively.

Leigh Taylor

Leigh Taylor is a senior social worker, social work consultant and trainer. She has promoted critical reflection on practice and improvement in systems at local and national level, with a special focus on child protection through engagement and collaboration between social workers, children and families. Leigh and her partner have a teenage son affected by a rare genetic condition with associated autism, learning disabilities, attention deficit, epilepsy, profound deafness and mood disorder.

I know as a social worker there will always be gaps in what we can do and provide. But, as a parent who happens to understand professional systems and am in receipt of a range of services for my son, this never seems "enough". As a parent and as a social worker I have thought about this disconnection. Ultimately parents are alone. They often feel isolated with grief, loss and anger, fear and a sense of injustice.

Standing at the top of the escalator in a crowded supermarket, where my son is having a complete 'meltdown', I am alone. It is not possible to reason our way out of the situation. Or fight my way out. Or to run. Under intense stress, in the eye of the storm, cortisol is pumping. The ability to think freezes. That's a problem for me…because I try hard to talk things through, explain things, to myself, or to others. In professional mode, I might try to 'negotiate'. But that's not much use for my son or for me in a crisis. He needs as few words as possible, repeated calmly and firmly. Nothing else reaches him. In these moments no number of services support or help!

For moments when I cannot think, I need steps that stay with me during the intense or accumulated intense stress. Get my son to safety! Ensure

others are safe, the environment is clear if he is kicking out! Stop talking. Keep signs few, simple. Remember to breathe! These are basic rules for me. I need them to be part of my cell structure.

Partners, family members (and colleagues) have varied reactions under intense stress. Partnership and teamwork depends on recognising this. So we all need to prepare by recognising how we jump, fight, shut down or retreat. Rehearse some of the small essential steps we can make. Rehearse things to avoid doing. I am a talker. Sometimes I need to stay quiet.

I transfer my own learning in to a small exercise with practitioners .In pairs I ask them to listen to each other talking about any issue of anxiety for just two minutes:

- Just listen. Don't talk or suggest anything.
- Then report back on POSITIVE learning from what they have heard. (Just positive learning from the other person's perspective. This goes against the grain. We are often 'hard wired' to swirl around adding to the cloud of problematic details already shared. By contrast, the aim of the exercise is to be deliberate and intentionally counter-intuitive.)
- Stop digging for information and suggesting solutions. There will always be learning from an alternative perspective. Appreciate what has already been shared.

Even when you are alongside in providing a service, the other person has their own path. Small steps are significant. They may seek help urgently. We may feel compelled to help and we may have professional responsibilities. But we cannot fix everything. We may have no power to change any of the fundamental circumstances. However, it can be valuable simply to take whatever time is needed to listen, recognise and accept the distress of the other person. Help them feel that they are not alone.

Anger, anxiety and despair may arise where the other person feels trapped, helpless, disempowered. Giving someone a sense that they have control over some immediate, small choices can be helpful and grounding. At the same time it can make a difference if the person feels you do care about how they are feeling now and about what happens next.

I find it infuriating when people make comparisons, or to imply that they "know what it is like". There is an important difference between sensitivity, recognition and implying that you've 'been there'. I cannot imagine what it would be like for a parent and profoundly disabled child in a war zone. It deeply upsets me to begin to imagine so many disabled children and their families trying to survive in or flee war in so many places.

With my own son's arrival, everything changed. Transitions for one person affect everyone close to them. Friendships, family relationships, work, values, ways of seeing, ways of coping, fundamental patterns like being able to sleep... For about three years we did not get a full night's sleep. Everyone has a different way of engaging and withdrawing. So it is helpful to think not just about the individual that is caring or needs help, but about the whole family experience – what their world is like from the inside out. Be willing to ask about this. People can sense kindness. That makes a big difference.

Jennifer King

Jennifer is an educational psychologist. She has had long experience as a practitioner in educational settings, independent work and in training in Scotland. Jennifer is also employed to report when a review of multi-agency systems and practices is needed in order to promote learning from high risk or harmful events.

I pay attention to 'community' dimensions in all my work with individuals, families, professionals and teams – the context of their relationships and experiences. In my early career in local authorities my focus was more exclusive and limited to individual functioning.

My concern about safeguarding and protecting children affected by disabilities has been strong throughout my career. The need for this attention has become more obvious to me as 'equalities' became more central to my practice. Risks of neglect, abuse and exploitation of disabled children can be accentuated in many different ways. The experiences of those most at risk are often unseen and unheard... And sometimes we assume they cannot communicate their experience.

I believe we all have to be critically reflective in relation to our own bias, the influence of the culture of the organisations in which we work. It is possible to make assumptions about people because they seem articulate; or because we feel compassion for them or grow to like them, or conversely because we feel unease, or antipathy for persons with whom we are working.

I often think about training that included video playback of my own interactions. That was long ago. But the memory of seeing and hearing my

own practice remains strong. Critical reflection on recall of work processes, in supervision, has also been valuable.

I often feel the need to step back and recognise my own reaction and consider how that is affecting my communication and judgement. Analysis of the different components of a situation requires this self-awareness. Some assessments of children and families can be compromised by lack of analysis and lack of self-awareness.

Listening may involve 'turn-taking'… reflecting back what you have understood … trying to reach a shared understanding. It can involve 'naming' what we have heard; and 'wondering,' aloud about what has been unsaid.

Listening may involve going slowly, step by step. I remember needing to meet a boy affected by Tourette's syndrome. He was extremely anxious. Gradually I learned that he feared saying something that would anger his mother and was under pressure to say what 'was expected'. He was in a corner. It was difficult for him to put words to this. Looking back I wished I had used non-verbal means to help him share his own story visually.

Sometimes listening involves providing scaffolding – step by step support. It also involves noticing and trying to understand how an individual communicates and adjusting to help them communicate their experience and feelings.

We aim to work in partnership, in collaboration, in relationship. But it is not always possible to agree on or to provide the resource that parents think is best for a child. Their feelings are often visceral. I try to be honest about reasons and respect differences. But at times the process is like a complex negotiation in professional disputes. We may have to be pragmatic, reaching a shared understanding about 'the best alternative to no agreement'.

In the middle of conflicted situations, I do try to remain calm, in my voice and manner, to 'self-regulate'. I am usually aware that I will need to be involved

long after moments of tension and conflict. Ironically one parent said that she could tell from my tone that I "did not care". The reverse was true. I was trying to be reasonable and navigate the intensity of my own inner reactions.

I try to think ahead, beyond my brief involvement, imagining the services and supports that a child and family is likely to need in the longer term. It is vital that whatever I do does not reduce their trust and engagement with other professionals that follow.

Thinking ahead also means trying to remain hopeful and working to sustain hope.

Jim Irvine

Jim was born in 1942. He trod a long and winding road into social work, which included work as a butcher and as a labourer. Building site conditions left him with a long-undiagnosed legacy of asbestosis. He spent many years in residential and local authority children and families social work and is known for an implacable listening style, combined with quiet, plain speaking. This meant that he would be sought after by colleagues, for example, when loud and angry situations felt suddenly out of control. Shaken carers, distressed children and stigmatised parents could also speak to him. Glimpses from his own pathway provide an uncompromising and critical perspective on discriminatory attitudes. He reflects on the underlying power of early childhood memories and persistent motivation to represent and fight for individuals and families who have been isolated, categorised, marginalised, cornered. Jim and his wife Susan's enduring and appreciative independence of spirit provide a positively challenging final story in this resource.

Recently I have recurring experience, often in the middle of life-stage conversation with my wife Susan and daughters Joelle and Isla. In mid-discussion I come to a shuddering halt, as though slamming on the brakes in an emergency stop. In that moment, I am transported back 82 years. The young Jim, just 18 months old, is in hospital. He has had his right eye removed and is feeling abandoned. My tears merge with his. I try to assure him it's OK. We did survive. We were loved. I'm eternally grateful for my small boy's courage then. It has remained inside and sustained me ever since.

Appearances. Assumptions. Fear. Judgements. Most powerful negative experiences have arisen where I have come across contemptuous,

professional class attitudes. Not from persons for whom I was providing a service, whom I have sometimes heard spoken of or spoken over as a lumpen proletariat, as a class apart.

Once a headteacher was disappointed to find only me in the waiting room. He saw a well weathered man with an eye patch. (After a sequence of glass and plastic eyes which had to be removed, I started to wear a black eye patch back in 1967). So he spoke over me to the receptionist, "Where's the bloody social worker?"

An associated memory: I am a big fan of the Scottish Children's Hearing system. However, I recall a Hearing where I was the social worker for a tall, thin, single parent Dad and his children. He had a punk style Mohican haircut and was registered blind. The Hearing was acrimonious. The Panel seemed intimidated, perhaps by appearances, perhaps by an adversarial lawyer for the mother, who was accompanied by her parents. I took a stand on assumptions made about the Dad. Back in the office I shared my dissatisfaction, perhaps in building-site vernacular. Some time later the Panel Members feedback filtered back to me through my manager. It had been suggested that I had over-identified with the blind 'punk', as I was 'half-blind'.

As I move into my 'end game' I have few regrets. To survive, I hook on to my dialysis machine for more than eight hours every night. Susan and I have adjusted together. We have had to. I am grateful for the gift of life. I know what my prospects would have been, had I lived in Ukraine or Gaza. I do not and have never considered myself disabled or handicapped.
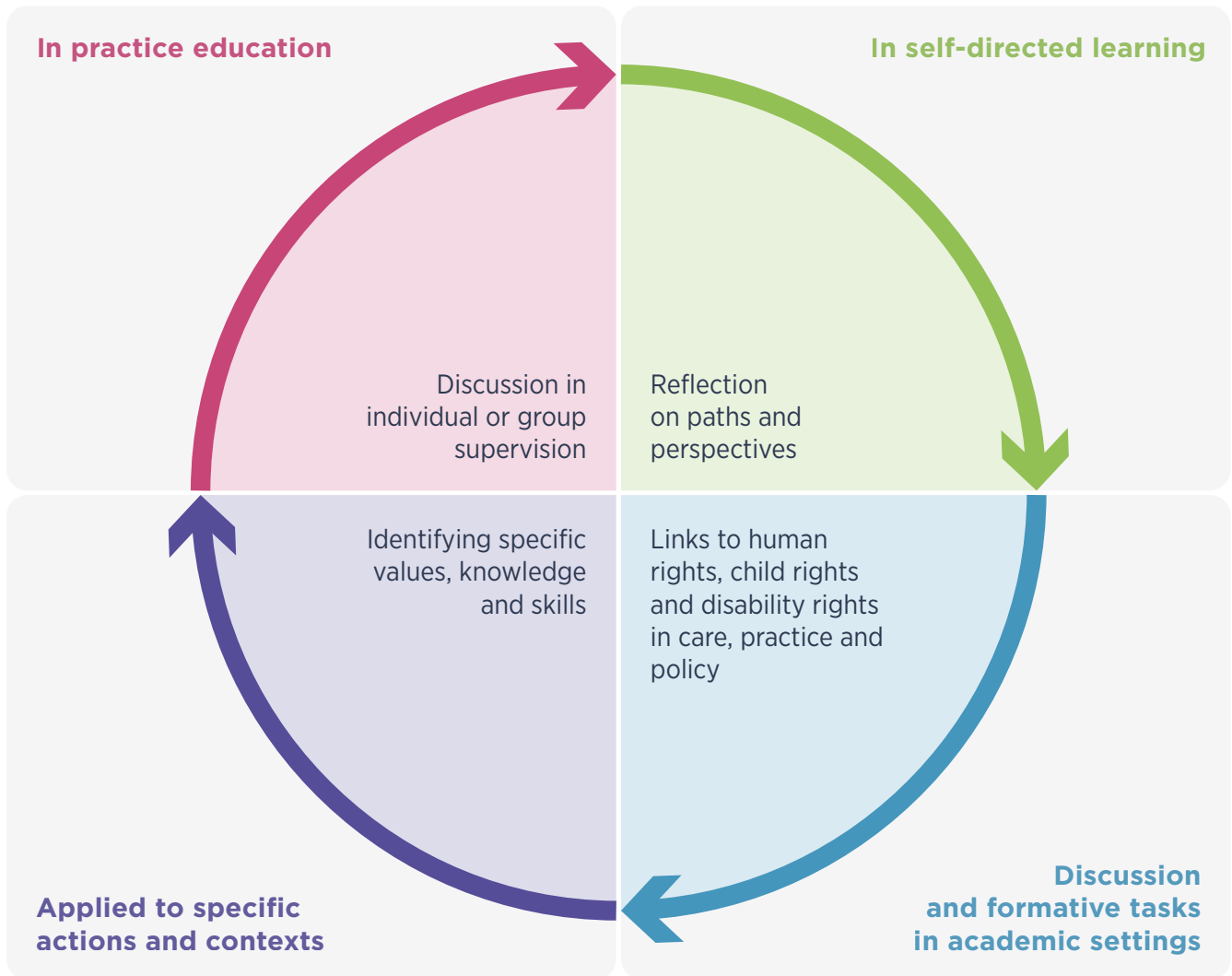
3. Using this resource

This section explores how this resource can be used and presents key themes for educational contexts and 'use of self.'

The resource can be applied in a flexible and targeted way to help connect classroom learning with real-world practice. At the same time, its potential extends further, to areas like team training and development, how we invite feedback, foster participation, and collaborate in shaping practice, policy, or research.

Figure 2 (below) demonstrates how the resource might be used to encourage critical reflection on both personal and professional beliefs and behaviours in a range of educational contexts.

In practice education

In self-directed learning

Discussion in individual or group supervision

Reflection on paths and perspectives

Identifying specific values, knowledge and skills

Links to human rights, child rights and disability rights in care, practice and policy

Applied to specific actions and contexts

Discussion and formative tasks in academic settings

Figure 2. Using the resource in context

USE OF SELF

Learning from the way we engage with 'disability' may have transferable value to all corners of social work and social care. The narratives in this resource encourage self-awareness in each situation. Figure 3 (over) suggests a range of processes which may be associated with critical self-awareness and use of self in context. Explanatory notes follow on from the diagram.

Figure 3. 'Use of self' processes and reflective prompts.

Preparation

Any form of work requires preparation and recognition of our role and responsibilities in a specific context. Our perspective of context is not the same as those who have been living the situation. Preparatory information may be scant and is always partial. Reflective preparation therefore includes an open attitude, attention to our own assumptions and recognition of the limits of what we 'know'. This lays the ground for listening.

Listening

Effective working relationships and any form of leadership is built through listening and the experience of being heard. As the stories in this resource imply, listening reaches beyond words to include recognition of the impact of history, relationships, conditions, discrimination, needs and strengths. It includes attention to the experiences of those who are less seen, those who are pre-verbal or whose voices are less heard. Which voices have been cut-off, over-ridden in conflict and isolated physically or emotionally? Listening includes self-awareness of our impressions, reactions, early assumptions and recognition of how our engagement is perceived and received.

Collaborative purpose

Real participation and co-production are dependent on honesty, on recognition of other perspectives, on a shared focus and sense of purpose. The experience of a working relationship may be valuable in itself. Depending on our role, working relationships are transitory, developing in challenging circumstances, for agreed reasons, at a time of transition or when teamwork and support for transitions are needed.

Bridges and barriers

In every transition and collaboration there are likely to be breakthroughs and hindrances in shared understanding and progress. The keys to navigating challenges might be practical, material, emotional, cultural. Self-awareness and attunement to the experience of others are likely to be necessary.

Signposts

In any situation there are likely to be signposts for the practitioner. In addition to the practice knowledge, professional and legal framework required in the circumstances,'signposts' may include critical integration

of intuition, of learning from peers, from supervision, of research and especially of feedback from those living the situation.

A constant process

The six hexagons of reflective prompts are laid out in a circle to suggest a constant process in which each element contributes to the others. The circle relates to reflective and reflexive practice before, during and after interactions – a continual, flexible and simple support for revisiting the meanings and choices in a situation for ourselves and others involved.

The stories conveyed in this resource weave many of these elements together as individuals and couples in contrasting roles and situations consider the meaning 'disabilities' has had in their development, motivation, work, care, and parenting over many decades. Their open attitude to sharing is a form of gift and provocation for practitioners, students and supervisors considering critical use of self in context.

Annex 1: Co-author reflections

Part of the collaborative approach in developing this resource was to capture from co-authors the impact of sharing their stories and those of others. This section presents a themed summary of their reflections.

PERSONAL COMMITMENTS AND STRUGGLES

One co-author expressed feeling "deeply impressed by the commitment shown by both individuals and couples in giving their perspectives," but also acknowledged the recurring themes of "pain and isolation, with moments of justifiable anger." Despite these feelings, the co-author emphasised the need for social workers to examine when "language… obscures and confuses individual and family experience." Several reflections touched upon the limitations of existing systems and the importance of advocacy. One participant highlighted how the resource provided valuable insights: "I was really not too sure of the purpose of the resource when we started, but what I read was really heart-warming… the varied pathways and perspectives reminded me how much 'reaching out' goes on under the radar." This theme of "reaching out" aligns with the notion that social work, when done thoughtfully and with dedication, can support individuals and families in profoundly meaningful ways.

THE ROLE OF PARENTS AND CARERS

The experiences of parents and carers, particularly those caring for children with disabilities, were central to many reflections. One co-author was "touched deeply by the sense of a parent's isolation… not feeling understood." Another participant reflected, "I was surprised at how powerfully it affected me emotionally," particularly in relation to their personal history with care-giving. They noted that the depth of commitment shown by carers, and they expressed admiration for the "good heartedness" and dedication of individuals sharing their experiences.

LEARNING THROUGH EXPERIENCE AND CULTURAL SENSITIVITY

One co-author shared how their own perspective was shaped through hearing the voices of others "I recognise gaps in disability studies and practices… methods and processes should be conceptualised and promoted to ensure that these people are heard, understood and recognised as experts in their own life." This theme emphasises the value of integrating "lived experience" into social work education and practice.

ISOLATION AND MARGINALISATION

A common thread throughout the reflections was the experience of isolation and marginalisation, which seemed to transcend national and systemic contexts. As one co-author reflected, "the experience of isolation seemed to be a common thread," and another noted, "how common, even universal, it is for individuals, carers, parents to feel isolated, marginalised and alone." The participant further questioned how systems, both in Scotland and internationally, often perpetuate these feelings despite resources and policies being in place. Another contributor acknowledged

how "even if we could not identify exactly amid this diversity of pathways and perspectives, there were similarities in all our stories."

THE IMPORTANCE OF ADVOCACY AND HOLISTIC APPROACHES

Advocacy emerged as an element in supporting individuals affected by disability. One co-author noted, "I worry for those that need but do not have access to competent advocacy. This is a responsibility for social workers – to try to connect people with advocacy where this makes sense and is wanted. Someone needs to be in their corner." This idea was echoed by another participant, who expressed, "I realise the value of... integrating 'lived experience' in developing learning, practice and policy," emphasising that advocacy must be genuine and effective, not tokenistic.

USE OF SELF AND HUMILITY IN PRACTICE

The concept of 'use of self' was also explored, especially in relation to how practitioners and individuals with disabilities perceive one another. One co-author reflected on their own personal experience with disability: "Someone once said – that the way we treat people with disabilities is a measurement of true or high functioning democracy." This prompted the realisation that "use of self may be complacent in social work... we always need an awareness of our own prejudices and awareness of what might stop us from engaging with other people and what might stop them engaging with me."

THE POTENTIAL OF THIS RESOURCE FOR SOCIAL WORK EDUCATION

The resource itself was seen as a tool that could enrich social work education and practice. One co-author expressed their hope that the

resource could "build confidence to explore and recognise everyday lived experience" and become "a tool for social work education and supervision." The diverse perspectives shared in the resource can help practitioners "respond at a deeper level, beyond categorisation of types and levels of need and of diagnosis," ultimately promoting a more holistic, human-centred approach to disability in social work.

Annex 2: Critical friends' reflections

This section presents reflections from eight critical friends from across different social work contexts to provide perspectives on the stories, their value and use.

1. DR. PATRICIA SILVEIRA DE FARIAS

Professor at Federal University of Rio de Janiero, Brazil, teacher of social work and sociology with a background in journalism; and a special interest in learning across cultures and borders; including comparative perceptions of disability.

First of all, this material is a gift. I sense that all those voices I heard tried to engage us in a conversation… and in an action to take part in a dimension of social life which is sometimes neglected sometimes. Participants create a resource from their own experiences. This is incredibly generous. It is like being taught by the older people in town, although some of these old people are not really that old. So it is an educational experience in the broadest sense. So I feel gratitude for this; and for allowing participative comment.

[…]

Bridges between our experiences are vital in all working relationships, especially when a person thinks, feels and functions in a way and in a context which is different or new to the listening practitioner. The task is to care with people, not 'about' them.

The popular saying, "*It takes an entire village to raise a child*," might be extended. It takes an entire network to care for a person and for carers.

Recognition and self-awareness

I have offered courses on accessibility and people with disabilities for social work students at my university. In the beginning I always suggest that there is no "us and them". People with disabilities include neighbours, colleagues, friends, partners, teachers, relatives and so on. After a time talking about this, with some examples, I ask if students know someone with some kind of mental health issues, or physical disabilities. In the beginning, the answer is always "no". And then, with the development of the course, some began to cite cases of depression, autism, or other issues as well, in their families, or within themselves. Some students presented a case from their internship at a hospital which a group of deaf young girls had attended because they had become pregnant. The presentation focussed on the shocked reactions of hospital staff who had somehow supposed that some disabilities excluded the possibility of reproductive and sexual lives.

I am now part of two committees at the Social Work School. One has a focus on 'accessibility'. The other is for students who struggle to write their compulsory research monographs. I suggested that the organisational structure of this second committee be changed to allow for a process of public presentation and inquiry to a board which considers issues relevant to the support of students with disabilities. Although in principle, staff sign up to principles of accessibility and inclusivity, technical and teaching staff on the committee were surprised and uncomfortable with this proposal. Their standard expectation is that, to be good professionals, students must be able to demonstrate skills in presentation and response to questions arising. However, the model is not inclusive because there are no reasonable adjustments for students who are affected by deafness, blindness, autism or impaired mobility.

So I think that the stories I read help me to engage in this kind of conversation more wisely. Recognition is important. To be aware of our own role and responsibility in each process and context is equally important. "Us" and "Them" are not separate categories in this field. Of course there are different positions and sufferings and achievements. We are all in some part at some point in a net or a web and it is necessary to see where and how we connect and are situated.

Lastly the Pathways resource also provoked some confusion and reflections on "professional" and "personal" boundaries. In some cultures, as in mine, for example, to smile (a lot), to touch, to look in the eyes and/or to refer to others in terms like "love", "my dear", "honey", "baby", are a common pattern in professional and in personal environments. So if I didn't behave this way, I could be considered as if "I don't care", as one of the people in the text puts it.

In Brazil, there are some studies which point out that black children at school felt less valuable because teachers usually only hug, kiss or address questions and comments to white children. They felt something like that their bodies are not as "loveable" as white ones. I wonder if this is not happening with children with disabilities, and at what extent. So it would be professional to look at the touching and gestures of kindness as not only personal.

However, in other cultures, these direct physical approaches can be extremely uncomfortable, or even offensive. And for some kinds of conditions, as in autism, to look right into the other's eye can be deeply upsetting. The context is always fundamental. However, it is inescapable that carers frequently have to manage or negotiate shared management of another person's body. The person they are caring for has their own perceptions of the carer's appearance, touch, smell, physical attitude. It seems essential to be aware of varied and differing perceptions and tolerances of 'boundaries' in each caring relationship. Critical reflection

on use of self includes development of sensitivity to boundaries that can seem semi-permeable. Some physical interactions may be an essential professional responsibility. Some such interactions may be experienced and expressed in ways that are distinctive and personal. At the same time carers and cared for persons may have a clear sense of what is necessarily private. Recognising and respecting privacy in the context of disability-related dependencies seems to be a vital element in relationships where power imbalance and vulnerability to abuse and neglect are latent.

2. KATHRYN YOUNG

Social worker and social work lecturer.

I have just finished reading every word of the Pathways draft. I found this powerful and moving and the co-authors' stories left me feeling humbled and in awe. This is valuable and inspiring for me in social work practice and education. It also provoked reflections on personal and family memories, interactions and circumstances, (and I am going to ring my Mam today!) The collaboration harnesses the humanity that should be front and centre to social work practice.

3. KAMAL IBRAHIM

Social worker with practice interest in multi-cultural family support, anti-racism and research experience concerning foster care and indigenous fostering in Ghana.

Overall I believe this collaborative resource will certainly challenge current perceptions and practices about disability. I found the personal reflections on experience of disability powerful and wonder how often people have the space to share this. A carer's account of how a young person with learning disabilities appeared to manage death and loss was also fascinating to me.

This seems to be an area that lacks attention in social work and research; and is an area of interest for me in work within BAME communities.

4. RICHARD WAITE

Independent child care social worker and consultant

A relief to find such wisdom. How could it be better reflected in organisational leadership? I see the focus in development of practice education. There is also an opportunity here to support wider learning and service improvement.

Tom Frank's remarks strike at the need and difficulty in changing fundamentals:

"Social work is not a series of procedures for work with types of person. Clients are people with whom we are in professional interaction. Not 'types' of person categorised by types or degrees of problem… This makes me realistic about how difficult it is to support the professional development of workers who are embedded in a rigid typology of service approaches, where social work is reduced to treatment, categorical entitlements and social administration."

These individual stories help to make conscious the personal elements we bring to relationships in practice. They illustrate careful integration of personal experience. I find it helpful to acknowledge that fear of personalising the professional may lead to a disconnect in our awareness and increase the risk of unconscious bias.

The resource prompts critical thinking about disempowering processes for parents and practitioners with personal experience of disabilities. I reflected on what it means to be "objective" in assessment, especially when the term disability is used to categorise thresholds and funding for services. The term can be misused to create and justify distance from the complex pathways. Diverse accounts illustrate the need to focus, in all assessment,

and in all social work services, on the relationships and perspectives of each person and each family in context. This includes sensitive attunement to messy, complicated aspects and patterns in relationships and pathways. 'Messy' can mean hard to understand, to know or to describe. Failure to do so – a lack of curiosity and concern about messy aspects in each situation – may lead to oppressive practice and outcomes.

Alongside these sensitivities, I was reminded of the need to be practical and realistic in situations where parents of children with disabilities feel isolated and at full stretch. These stories and reflections remind me to focus on that which families identify as realistic, useful and resilience-building.

5. MELANIE DUROWSE

Social worker, programme convenor and lecturer in social work.

In this resource, hearing first hand voices gave me such an insight into their experiences. In discussions I was surprised about the areas that they felt were most significant and wanted to discuss. This made me reflect on how often we focus on the areas we think are relevant and possibly don't provide the space for people to talk about the deeper impacts of their experiences. I think this will be an excellent resource for students. The personal stories allow the reader to be immersed in candid and mature reflections in a way that can't be achieved without first hand accounts. It's a remarkable resource, and I hope to be able to use it in the classroom.

6. ANDREW MURRAY

Director, Trail Consultancy. Former Programme Manager for Safe Families in Scotland.

Many resources and papers in social work and social care are dry and academic. 'Disabilities: pathways and perspectives' is not. It is moving, insightful and very challenging. Pathways are personal and professional. Hearing international perspectives is fascinating. As a practitioner with 30 years experience, this gave me new and fresh insights into children with special needs and the amazing persistence and resilience of their carers and advocates. Many themes are depressingly familiar: the struggle for inclusion, the fight for adequate services, the battle against procedure and protocols that can dehumanise and crush the human spirit. But what shines out from these pages is love and hope.

The participants are those who see beyond labels and stereotypes. They see success as more than tick boxes and traditionally measured outcomes. As Dr Kateryna Buchko says, 'Success includes the distinctive experience for each person of belonging, being known, being accepted.' A big theme that shines through in this resource is how many parents and carers feel sidelined by professionals and services. This is a timely reminder to those of who are professionals that humanity, empathy and compassion can be just as much, if not even more powerful than the services being offered. So often services offered are in silos.

As Ronnie Hill observes,'We need to try to tune in to the whole ecology of people's lives in order to understand what part 'disability' plays in their needs, rights and struggles.' He has found that no amount of helpful resources and systems can replace the energy and integrity of local practitioners when

situations and services are very complex. High quality leadership and good quality training are key to better services. This is surely something we need to remember as we seek to absorb cutbacks and redesign services.

This resource is rooted in the core social work values of equality and inclusion is an important reminder that as practitioners we must always be led by those who we seek to serve. This resource reminds us that we have so much more to do to make sure that the most vulnerable in our society have the opportunity to belong by being seen, heard and understood.

7. MELANIE STONE

Social worker and project consultant who has worked in the statutory and not-for-profit sectors in Scotland and Northern Ireland for 25 years.

The resource is easy to engage with and it is useful to have insights from professional, research and personal experience (combined), practice and policy. This gives a rounded and human picture, also addressing some big questions about structures and social policy. I also like that it challenges the reader, but isn't so high-minded as to be intimidating. At some points it reflects practitioners' sense of failure, while giving a sense of the relentlessness of people striving for better. I felt the warmth shines through some pathways; and in others it was the fight and articulation of inequality that stayed with me.

Analysis and categorisation of content seems very usable, and helpful to the practitioners, which is what I look for. Among the quotes I found memorable: from Ronnie Hill – *"We need to try to tune in to the whole ecology of people's lives in order to understand what part 'disability' plays in their needs, rights and struggles."* I love this statement. And this one… from Bob Fraser – *"I encourage colleagues not to fixate on uncertainties of fact in 'assessment', rather to understand how the child or adult experiences*

their world." I loved his whole piece. Tom Frank's candid self-reflection made an impression on me. We don't often see that level of humility. The short paragraph on Jimmy McIntosh in his piece is very impactful, though shameful. Some accounts made me want to ask more questions and learn more about each situation. I wished I had had access to such challenges and reflections in earlier stages of professional training.

8. BEENA VEIRAIAH & DR ARVIND VEIRAIAH

Beena Veiraiah is a social worker with experience in England, Scotland and India, with special interest in fostering and mentoring in school context. Dr Arvind Veiraiah is a consultant in acute medicine and toxicology.

Beena Veiraiah: As a practice educator in social work, I feel this would be useful to support learners' reflection and understanding, provoking discussion and assisting collaborative decision making. The narratives and reflections are a rich resource and the way they are brought together in the table was helpful. The title concept – *Pathways and perspectives* – was helpful in itself and different from a usual frame of 'enablers and barriers'. I would use this resource as a support for discussions on systems, access, mental health, acceptance of disability differences in approaches and motivations.

From a personal perspective I feel that non-white professionals and service users experience an additional complexity in dealing with disability. Cultural differences compound the language and resource issues described here. For example, I recall the case of an Asian immigrant child with a learning disability, whose care was thought to be deficient because they were eating on the floor.

As a 'minoritised' professional, I also bring a life experience of alternative models and perspectives that may be of value in some cases, whether the users are white or not. For example, in Scotland, an Indian friend's disabled

child benefits from a large community group, who meet regularly with all ages combined, equally welcoming people with all ages and stages. On the other hand, the family had very little knowledge on how to advocate for services for their daughter, for e.g., a rebate on council tax. They simply accepted a 'no' without seeking more help or appealing the decision. Having the help of a friend and advocate with professional understanding of social services allowed them to find support that they would not have been offered otherwise.

I am currently working in a school in India and am considering trying the approach in this resource to explore issues here in the school with the staff, parents and children.

Dr Arvind Veiraiah: This is a highly thought provoking and informative account and exploration of experiences and perspectives of people who have been in leading roles and had deep engagement with disability at a personal and professional level. The combination of breadth and depth allowed me to understand more by comparing and contrasting experiences, reactions, actions and outcomes.

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