Braiding hopes and intentions with disabilities and their networks of fa

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We work with colleagues in a systemic and narrative informed team that is part of a multidisciplinary outpatient-service for people affected by intellectual disabilities. The people using these services are usually connected in large networks of relationships with family, carers and a range of practitioners providing health, mental health, social care and education services. The more isolated the individuals are from family or community, the more services seem to be involved. Working from an assumption that we can accomplish more within a network of collaborative relationships than each on our own, we work towards co-creating 'resource-full communities' of clients, families and people involved in their care so that we might pool the abilities of everyone involved (Fredman, 2007).

For example, we were asked for help with Lisa J (aged thirty-one) and her family by Lisa's care coordinator, Sally, a community psychiatric nurse. (All names and personal details are changed to assure anonymity of people). Lisa had recently been discharged from a highly specialised and highly resourced psychiatric inpatient-unit after nine months. She had been admitted following episodes of *"violence associated with mood swings"* and had been given a diagnosis of *"bipolar disorder"*. The nurse, Sally, complained that Lisa's parents were *"not supporting Lisa's care plan"* and were *"dissatisfied with the poor service their daughter was receiving"*. The psychiatrist was monitoring Lisa's medication and, since her discharge, Lisa was attending a day centre and an employment project.

We have evolved our network approach with colleagues over the past twenty years. Elsewhere we describe our work with older people (Anderson & Johnson, 2010) and young people (Fredman, 2007, 2014) to promote 'open dialogue' (Seikkula & Arnkil, 2006) to help those involved find new ways of understanding and of seeing things, opening the potential for acting and interacting differently. Our practice is rooted in systemic (Cecchin, 1987; Cecchin *et al*., 1992; Boscolo *et al*., 1987), constructionist (Anderson & Goolishian,1992; Cronen & Lang, 1994) and narrative approaches (White, 2007), in particular Tom Andersen's work on reflecting processes (1991, 1995). More recently, we have drawn inspiration from Jaakko Seikkula's open-dialogue work with large systems (Seikkula, *et al*., 1995). We see our approach as sharing what Wittgenstein (1953) would call a 'family resemblance' with open dialogue in that we give careful attention to the twelve key elements of the approach described by Olson, Seikkula and Ziedonis (2014). We particularly privilege 'dialogue and polyphony' and 'tolerating uncertainty' but our poorly resourced inner city London outpatient context hinders our capacity to adhere with 'fidelity' to all seven optimal principles of open dialogue, especially those that emphasise the organisational features of the system, like 'immediate help'.

In this article, we describe an aspect of our practice whereby the conductor (Henrik) co-creates a focus for the meeting jointly with the client, Lisa J, and her network of family and practitioners, through 'braiding their hopes and intentions' with stories of progress and with ideas and suggestions to open space for ways to go on. Our approach involves teamwork; Glenda, Bethan Ramsey and Joel Parker were team members who offered reflections (Andersen, 1991) during the meeting.

People affected by intellectual disabilities often find communicating a challenge and their voices are frequently subjugated or silenced. Therefore, we try to bring forth and value the voice of the person with intellectual disabilities alongside the voices of their carers so that all those present can feel understood and appreciated. Our intention is to open space for communication, understanding, appreciation and respect, not only with each person but also between the people present. Inviting others to take into account the person identified with intellectual disabilities as a person who can think, express and choose, also slows the conversation, thereby opening space for what Tom Andersen (1995) calls 'reflecting processes' each person having the opportunity to hear the different perspectives of the other. Baum and Lynggaard (2006) and Webb-Peploe and Fredman (2015) offer a repertoire of systemic practices for hearing and including the voice of the person affected by intellectual disabilities in family and network meetings.

We invited Lisa, her mother (Anne), her father (Lionel) and members of her network comprising the manager of her day centre (Diane); key worker at the employment project (Jim); care-coordinator (Sally); outreach worker (Naima) and family psychologist (Tim) as well as her psychiatrist and day centre key-worker who were not able to attend. (See Figure 1 for Lisa's resource-full community). Following introductions whereby Henrik had woven a textured net-work of relationships with Lisa, as the weft or thread introducing and connecting everyone present, (Fredman, 2014) he invited Lisa to tell us what she wanted from our meeting.

Co-creating a focus for the meeting

To ensure we use the time to talk about what is relevant and useful to all, we aim to create the focus for our conversation jointly with everyone present rather than assume we know what needs to be talked about or follow the agenda of one or two people (Stott & Martin, 2010). Informed by our intention to engage from the start in talking about people's hopes and purposes for the session and for their lives, we usually begin with future questions. We often invite people to consider the outcome of the consultation from a time in the future where the 'problem' is not around, to open space for people to start anticipating solutions right from the beginning of the meeting. For example, we might ask questions like, *"Imagine we are now at the end of this meeting and you say*

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to yourself 'That was very useful. Now I know how to go on'… What have we discussed here today? … What have we sorted out? … What are you able to do? What have we made clearer? What have we worked out together?" Or, *"Let's say it is a month from now and the dilemma that has brought you here is resolved. What is happening? What are you pleased about?"*

Since people affected by intellectual disabilities have frequently experienced failure in learning, in achieving or answering questions compared with their similar-aged peers, we take care to coordinate our language with 'curiosity' using our voice and our body to communicate respectful interest rather than intrusive investigation. Mindful that Lisa's vocabulary was not as extensive as his own; that she took time to process what she heard; spoke slowly; had difficulty following complex sentence-structures; could not make sense of our construction of time, especially hypothetical questions, and could not hold more than two key ideas in her mind at one time, Henrik recognised the need to create a 'scaffold' so as to make future questions accessible to Lisa. Therefore, after asking a few questions that did not connect, he tried, *"What do you want us to talk about here today?"* to which Lisa replied, *"Doing new things …"*

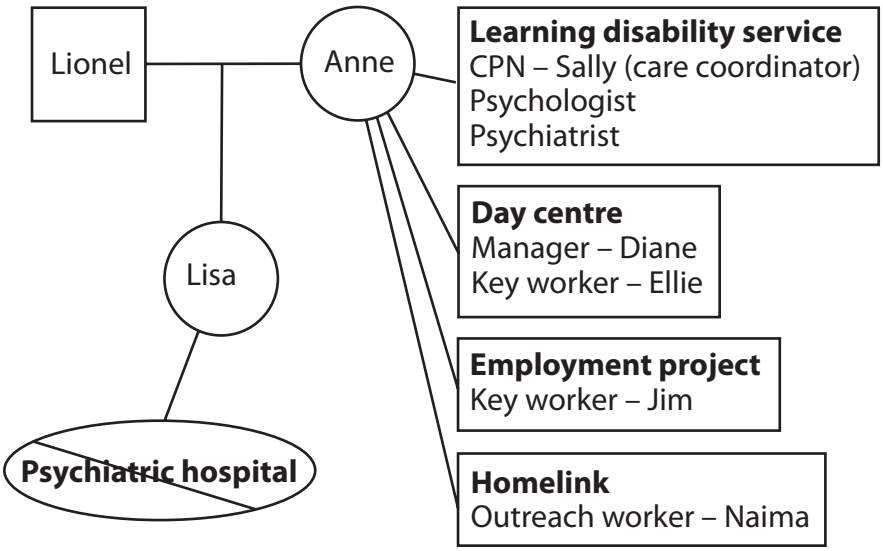

Figure 1: Lisa's resource-full community

Tuning in to language

We try to enable a conversation that first invites understanding and witnessing rather than looking immediately for agreements or solutions. We recognise that each person affected by intellectual disabilities has a unique experience of the world and acts out of many different contexts quite different from our own. Therefore we are cautious not to assume we know how they experience their world. To help us avoid assuming too quickly that we understand exactly what people are asking for, and to help us coordinate and connect different agendas, we tune in to the key words or phrases that people use, thereby 'joining their language'. By 'key words', we mean words or phrases that seem to carry important meanings for the person. They are often associated with non-verbal expressions like pauses, change of voice, tone or pitch, intonation and body posture. They seem to call for a response and they touch or move the speaker and/or the listener.

Therefore, simultaneously talking and writing key words on a large sheet of paper with a favourite coloured pen that Lisa had chosen, Henrik noted ***"Do New Things? You want to do new things?"*** Giggling, Lisa looked at Jim from the employment project and asked, *"Do I? You say so"*. (Key words that Henrik noted on the paper are presented in **bold**.)

Approaching each person's meanings as unique to them, we check our understanding of words they use, sometimes inviting people to go inside the word to look at what else is there to further coordinate meanings and open space for new ideas.

Continuing, Henrik repeated: *"**New things** – uh what is 'new things'? Do you know about 'new things' Lisa can do, Jim?"*

Jim: *"Lisa needs to take a **few more risks – step out of her routine** a bit. We have been thinking about … "*
Lisa: *"The Christmas party – I want to go to the **Christmas party**."*
Henrik: *"Is this an example of a new thing – or something else?"*
Jim: *"I guess … though … "*
Lisa: *"It's new – I **never went before**."*
Henrik: (writing down and repeating 'take more risks', 'step out of routine' and 'Christmas party'): *"Anything else. Uh – this word – 'new things' – where does it come from – who said it first?"*
Lisa: (giggling and pointing at Jim).
Henrik: *"Let me check if I understand. Is this what you would like us to sort out today – to talk about today?* (Pointing to the words) … *how Lisa can take new **steps**, **do new things** she has **not done before** – like going to a **Christmas party**… "*
Lisa: (nodding).
Jim: *"Yes and ….. **emails** …..using the **computer**."*

To ensure he was coordinating with Lisa and focusing on what was important for her as well as her network, Henrik summarised to check his understanding,

relying on her verbal and non-verbal feedback to tell him whether he was on the right lines. He summarised tentatively to offer the possibility of others correcting or altering what he had said, ensuring that they were co-creating rather than him imposing *his* meanings.

Double listening for frustrated dreams

Sometimes, it is very difficult for people to tell us about hopes or wishes, especially when the weight of problems is clouding their vision of the future. Lionel was overwhelmed with concern for his daughter and frustration with services and, despite Henrik's gentle invitations to look beyond the current problems, Lionel could only repeat his frustrations in a critical tone, *"We never get any feedback … we get nothing from your community based services … not like the review we got at the hospital … we had that regularly … here is it is just monitoring and follow-up. What is this! It is pointless!"*

In situations like this, we engage in double listening, trying to tune in to the beliefs, values, hopes, principles and commitments that are 'absent but implicit' (White, 2000) in the person's expression of dissatisfaction, complaint or frustration. By becoming curious about Lionel's 'frustrated dream' (McAdam & Lang, 2009), Henrik tuned in to what was 'absent but implicit' in Lionel's statement including his wish for **feedback** – that **has a point** and his commitment to collaborate with **community based services** through **regular reviews**.

Thus, each person in Lisa's network heard what each other wanted from this meeting and Henrik repeated, and noted on the paper, key words and phrases that pointed to their intentions hopes and the values important to them.

For Anne, Lisa's mother this included, *"**Keep Lisa's health** … **staying well**"*. Diane the day centre manager wanted to *"Look at **what Lisa has achieved** … Make sure it **stays positive**"*. Jim wanted to *"**Meet people from the day centre** … Get an idea of what **Lisa is doing there**"*. Sally, the care coordinator noted *"We all work in **isolation** – we don't **often meet up** …… to **hear how each service is going**"*. Naima, the outreach worker wanted *"much the same … See **how things are going**"* and the psychologist, Tim, added, *"Lisa's parents have told me that something important happened when Lisa was an inpatient. She **developed her own voice**. A huge amount of work went into that – I would be interested to **learn more** about that"*.

To keep Lisa at the centre of the discussion, Henrik asked for her opinion or to check details, for example, *"So, some things have gone well with Lisa? And Diane wants to hear about this. Can you tell us what has gone well, Lisa?"* to which she offered numerous examples including *"Went to town … took two buses … Naima took photos … Sold so many sandwiches … "*. Naima added that *"Lisa really enjoyed it"* and Jim elaborated, *"She was sandwich salesperson of the month"*.

Drawing threads

As he wrote down each person's key words, Henrik tried to cluster them into threads or connecting themes (see Figure 2). We find we can only begin to understand the meaning of the person's words when we know how to use them in the particular context we are talking. Therefore, once Henrik checked we had heard the contributions of everyone, referring to the mind-map of key words he had created with the network (Figure 2), he drew out each thread in turn, emphasising their words: *"You all want to hear **how Lisa is doing**: what is **going well**, what **she has achieved** so things can **stay positive**; so Lisa can **keep her health** and **stay well**. You are keen to **meet up** together so you can share **feedback from community services** and **review** in ways that **have a point** and prevent **isolation**. And you would like to **learn** from what the **hospital** did to help Lisa **develop her voice**. We heard that Lisa is already **doing new things** that she has **not done before** and you are talking of trying other new things like the **Christmas party**, **emails** and **computer**. Is there anything else you want to add – that you would like from our talking here today?"*

Summarising our understanding in this way also helps us check whether we

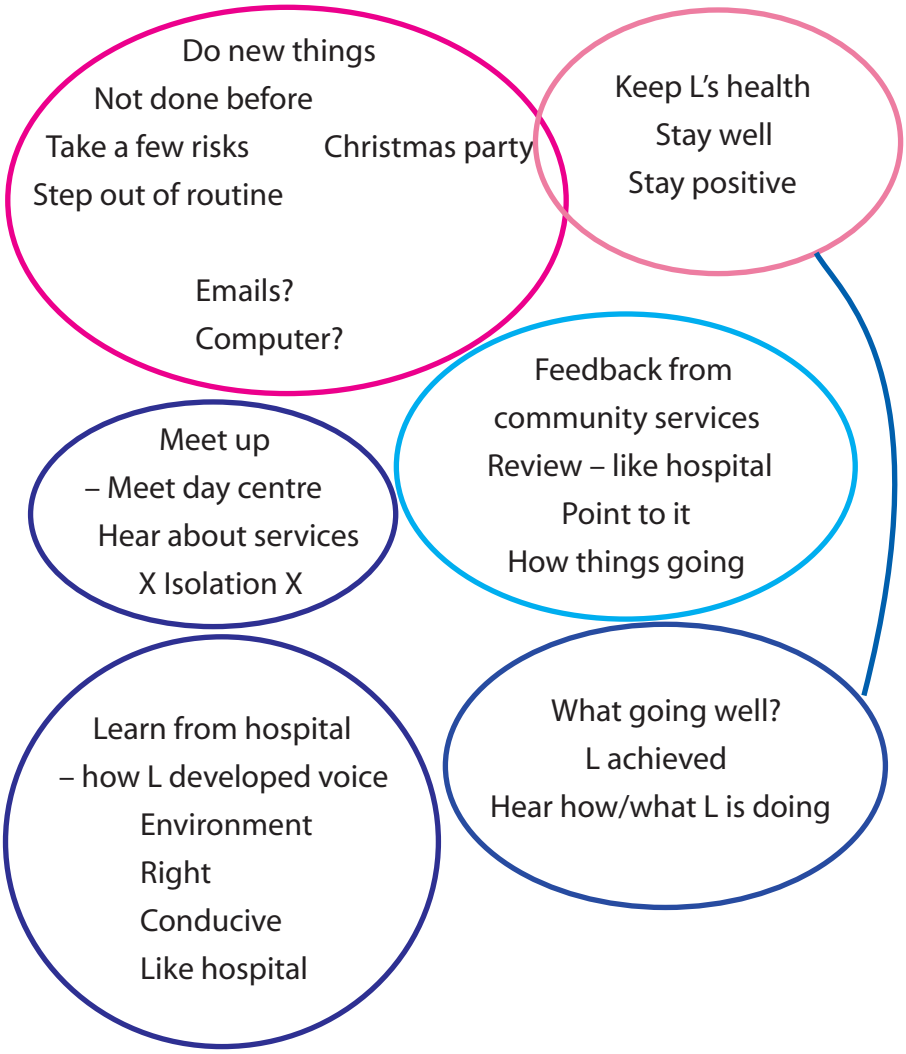

Figure 2: Threading key words

are co-creating meanings or imposing our own. Each person nodded as they heard their own words, as if to confirm we had understood. By welcoming all contributions, acknowledging with interest and appreciation when there is a difference and thus managing the 'tensionality of dialogue' (McNamee, 2005, p. 77), the conductor can coordinate the multiplicity of views in the room. For Cecchin (1987), it is in this dialogic space where different beliefs, hopes and meanings co-exist, that therapeutic change happens. Making it possible for the family and practitioners to juxtapose their different ideas, to hear each other's views, and to have their own thoughts as they are listening, opens space for different contributions and new ways forward to emerge. Hence, witnessing his daughter in the appreciative space that had been created, Lionel went on, *"Lisa has maintained her level – she is still improving. When the environment is right then Lisa thinks.* ***The environment*** *was definitely* ***right*** *in the hospital, it was* ***conducive*** *– and now it is conducive at the day centre and work project"*. Henrik threaded Lionel's key words that struck him (in bold) on to the mind-map.

Braiding intentions with resources and plans to go on

We go on to follow, in turn, each thread that holds the hopes and values of the network, asking, *"So what have you already done?"* and then *"What other ideas do you have?"* For example, Henrik asked, *"So what is Lisa doing that is going well?"* and then later, *"What ideas do you have about meeting up to hear about each other's services?"* Lisa and her network generated a long list of her achievements which led her father to further witness, *"It is excellent to see her letting her feelings be known … having a sense of humour ... saying what she wants"*, and for Diane to witness her *"pleasure to see Lisa glow"*. Lisa said she did not know that people noticed this in her *"… not really. But it is a good thing to hear"*.

Henrik further brought forth resources to the situation by exploring what people had done to make progress possible. (Sometimes we ask what people have done to stop the situation getting worse). Practitioners suggested that *"Lisa should take credit … she developed confidence … was able to trust the day centre and Naima more … was clear she would always have choices… parents have put a lot into getting what is best for their daughter … built on progress from hospital admission"* and her parents added that *"The hospital environment gave her stability and psychological grounding"* and that *"The meetings with the psychologist and community psychiatric nurse are very helpful"*.

In the final part of these meetings, ideas and offers come fast and thick. For example, when Henrik asked how everyone would *"build on this and keep this therapeutic environment going in the community?"* the nurse offered the parents regular meetings; the day centre and employment project arranged to liaise and prepare joint review-meetings; the employment project worker offered to *"make a DVD of what Lisa does at the employment project so everyone can learn about developments"* and the family psychologist offered to keep the psychiatrist *"in the loop"*.

Recording and documenting

The team catches and records each achievement, idea or suggestion in writing as they are generated in the meeting. When people offer recommendations or suggestions, we always ask, *"Who will do that? Who can join them?"* so we can document a person's name next to each 'action plan'. Thus, the conductor goes on to interweave or braid the threads holding the intentions, hopes and commitments of everyone present (practitioners and clients) with stories of accomplishments into a plan of action; a way to go on.

Leaving the meeting is never the end, particularly for the person who has to document it (Anderson & Johnson, 2010). We always provide a written record of the meeting for those present and those unable to attend. We record progress reported in the meeting in detail, since witnessing achievements and acknowledging how these were attained make an important contribution to consolidating developments. The written record reflects the future focus of the meeting by documenting who has agreed to do what and when.

We attend carefully to the language we use in our written record. Where we can, we use the actual words of the participants in the meeting, avoiding jargon and medical terminology where possible. We often discuss who can convey the written communication to the client affected by intellectual disabilities and how we might make the document accessible.

Weaving net-works of hope

Over the years of practising in public services, we have noted how challenging problems can create an overwhelming sense of hopelessness for people like Lisa and her parents. We have also witnessed how hopelessness can lead excellent practitioners working in isolation, with limited resources, into apathy or numbness that can interfere with their ability to witness the experience, achievements and hope of the people they work with. Many of the practitioners working with Lisa arrived at this meeting overwhelmed by that sort of demoralisation, with the effect that, initially, they were intent on passing on responsibility for the work to another or to *"close the case because she is treatment resistant"*.

We have found this process of braiding the threads of people's hopes, values and intentions with stories of progress, achievements, ideas and suggestions can open space for ways to go on. Since telling and witnessing stories create contexts where it is safe to share values that reconnect people with the hopes and principles with which they want to be identified, there is the potential for this braiding to touch and move each other. We have found the process of creating net-works of resource-full communities can generate energy and creativity between people, creating contexts where we can 'do hope' with each other (Weingarten, 2010).

It is in these sorts of conversational spaces that untold stories like Lisa's developing voice, confidence and trust can be told and where it is possible for people like Lisa and her parents and also the practitioners involved to perform their preferred identities and be witnessed and celebrated as the sort of persons they want to be. Hence, we have seen these networks of hope offer antidotes to demoralisation so that people find enthusiasm and innovative ways to stay connected. At the end of the meeting, Lisa's mother, Anne, said that *"communication avenues are cleared"* and Lionel added, *"This feels like a well-oiled machine – in the past we had breakdowns and creaks – we can keep going and checking in with each other"*.

From left to right: Henrik Lynggaard, Glenda Fredman, Bethan Ramsey and Joel Parker

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