

Reconnecting Hearts and Minds

A Paradigm day of conversation about **ensuring good support** with and for people with learning disabilities

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John O'Brien compiled these notes based on his record of large group discussions. Not everyone will agree with each point and many good ideas from the small group discussions are not recorded here.



I don't care as much about how payments are arranged as I do about the person who comes into our life to offer support. I want a support worker who connects, understands who the person really is, and opens and supports possibilities for a meaningful community life.



This image, the center piece of a quilt constructed by direct support workers from New York City with Beth Mount, expresses their belief that the work of assisting people with disabilities is meaningful when it engages mind, heart, and hands. See John O'Brien & Beth Mount (2005) *Make a difference: A guidebook for person-centered direct support*. Inclusion Press www.inclusiononline.co.uk/books_mone.html

This paraphrase of a mother's comment to Sally Warren set the topic for the day's conversation.

In an important way, the value of public investment in social care comes down to the capacity to bring respectful, trustworthy people into the lives of people with learning difficulties and their families. People who are able and willing to learn how to connect with and come to understand a person and join that person to discover and make the best of opportunities for a meaningful community life.

Our concern is that current trends threaten to split the work of offering assistance from its sources of meaning and effectiveness: the working together of minds, hearts, and hands in support of a satisfying community life. Actual and potential funding cuts create a climate of uncertainty that increases fear and encourages mechanistic, transactional approaches to assisting people. At the same time, increasing regulation takes over more and more time and redirects attention from the life a unique person wants to live to the rules and procedures governing paid assistance. Under these conditions, assistance collapses and becomes a matter of following directions while completing a list of standardized tasks and chores in a rigorously risk managed space that too often trades off opportunity for community participation and the exercise of autonomy for liability avoidance. Instead of being challenged to build a respectful relationship in which they can listen more deeply to and act more creatively with people with disabilities and their allies, support workers are expected to comply with more and more detailed rules. Mind and heart are squeezed out. Only tasks are valued and value is seen primarily in terms of money cost.



Appreciating good support

In groups of three we told and reflected on stories of support at its best. Groups finished their inquiry by creating images that represent the living core of good support. Some of these are above.

Themes expressed in the images include: listening with care for expressions of the person's identity, abilities and interests; promoting the person's right to choice and self-direction; respecting the person's current relationships and taking intentional action to widen and deepen the person's social network; risking creative and assertive action to overcome barriers to community participation. Many of these images celebrate the heart and the ears, identifying relationship, commitment and honoring the person's voice as the medium for offering good support.

Good support relationships don't just happen and they are not always easy. Trust grows from deep respect for the person and their rights to pursue a life that is meaningful to them. This respect demands authenticity and transparency as well as reliability in living up to agreements and holding the person's assets, confidences, dreams and plans in trust.

At the core, trust grows when support workers act from a wholehearted effort to see the whole person as the person is and potentially can become. This is not a matter of assessing the person at a distance so much as the result of openness, attention and imagination to see, hear and feel the person. Such openness takes free time, time that is not completely filled and accounted for by externally prescribed tasks, time that the people involved can choose to invest in discovering how to get more of what matters. Such free time does not neglect a person, it offers a space for action and learning.

Transparency demands acknowledgement of the limits imposed by the role of paid support worker, but within the boundaries of the role it is typical for effective workers and those they support to come to like each other and for workers to be able to identify a



It's great when a person can shift from feeling like they have to have a staff person around them to wanting the support person there because they are getting just what they need to do things that are really important to them. One is just getting through the hours, the other is having a life.

—A person who receives support

variety of ways in which they have personally benefited from the support relationship in terms of their own growth and development. Learning is mutual and not a matter of the support person imposing some impersonal procedure. Even teaching a skill, when this is called for, involves collaborating with the learner to find the most effective path to mastery. Resolving conflicts, when they occur, calls on and provides occasion to improve the emotional intelligence in the relationship.

Rights only become real when they turn into practical steps that people and their allies and support workers take and learn from together. Respect opens a space in which it is possible to listen for a better understanding of what matters to the person. What is revealed by careful listening often points the way to opportunities worth pursuing. Given how powerfully people with learning difficulties have experienced social exclusion and its negative effects on perception of a person's potential, it makes little sense to pre-judge what is possible for a person. It is necessary to give up the role of expert on what is "realistic" and hold uncertainty about what can be achieved in a productive way. Acting creatively from a position of not knowing until we make our best tries doesn't guarantee success by any means, but it is almost always a better starting place than giving up without taking a step. Fear of failure is understandable, but strong alliances support resilient responses.

Moving toward meaningful opportunities usually reveals barriers to deal with. Sometimes these barriers arise from practices and policies of the service organization that employs the support worker. An effective organization will embrace values and methods that make it flexible in meeting new demands. One of the most important sources of adaptive flexibility is the capacity of people in the organization to notice and escape the defensive routines that can mask possible changes by blaming external forces and claiming powerlessness (Commissioners won't let us. Inspectors will get us.) or dismissing a new possibility as infeasible or unimportant. Honestly facing organizational incapability and assumptions that undermine belief in people with learning difficulties and their allies is an important opening toward learning.

We are concerned

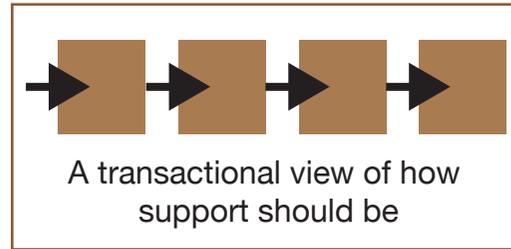
Scarcity can favor a transactional view of support over a relational understanding. A transactional view imagines support as a sort of commodity that can be measured out in instrumental tasks and assessed by immediate outcomes. All of a support workers behavior is "on the purchaser's clock" and under control of plans and procedures

approved by the purchaser. This assumes that the knowledge necessary to identify and provide what's needed is complete and available to those responsible for approving plans.

In contrast to the transactional view, good support as people experience it is a human relationship supported by public funds. One critical aspect of this relationship is the reliable and competent performance of a paid role that includes necessary assistance tasks. But there is more. The ups and downs of a respectful and mindful relationship will create new knowledge of capacities and interests and identify new possibilities to try. The human dimension of support happens "off the clock" though within work time in the sense that it can't be programmed from a distance, though the guidance and support available to the relationship can encourage or discourage the quality of the relationship.

As public funds grow tighter and controls get more complex, fear of error grows. The judgement of people in professional and managerial roles, who are more distant from the contexts of support, shapes more and more of the work life of those who are with people. Low frequency and distant events, like institutional abuse, can set off a chain reaction of policy responses aimed at even more tightly controlling risk. Big strategies for stretching scarce money can interrupt the flow of relationships that make support effective. Even ordinary moments, like sharing a cup of coffee or receiving a small gift can fall under a summary judgement of impropriety. This distrust of those immediately responsible for recruiting and supervising support workers, people who can have the first hand knowledge to question gift giving or any other conduct, undermines the intelligence of the whole system. Concern over judgement from a distance can also lead people to believe that there are perfectly ordinary aspects of their relationship that need to be covered up. This inhibition can be strong even when a person who receives support does something thoughtful or kind for the person in the role of support worker. This kind of censorship reduces knowledge of the person as the person actually is.

When fear of error or passivity in response to distant authority lead support workers to pull back from acting on the knowledge that grows from their relationships, the risk increases of compromising people's rights to live as they would value living.



Providing organizations can make a difference

Organizations that provide services have important contributions to make to good support relationships. These contributions depend on a clear understanding of the imbalance of structural power that disadvantages people with learning difficulties and their families and allies. Despite legal assertions of rights, many people's capacities to live out those rights depend on system decisions about allocation of funds, policies governing contracts and regulations intended to promote quality and manage risk. Organizations that act as if these external forces overtake their capacity for independent action and their ability to confidently engage in discussion with commissioners and regulators are likely to take a passive, victimized position. This can polarize into a good guys/bad guys story in which the bad guys win and the good guys are powerless and must simply do what they are told.

In relationship to commissioners, designers of regulation and inspection standards and procedures and other policy makers, their leadership can...

- ... resist the competitive pressures that promote isolation and reach out to form alliances with self-advocates, family advocates, other service providers and aligned commissioners aimed at actively promoting the conditions necessary for good support.
- ... be assertive about the highest purpose of public investment in supports to people with learning disabilities: the promotion of autonomy and active citizenship.
- ... be articulate about what they know about effective support and the conditions necessary for good support relationships to flourish.
- ... analyze the potential costs of those competitive tendering practices that fragment support relationships and undermine commitment and continuity and participate in or create forums to make changes.
- ... identify counterproductive forms of regulation or risk management and find ways to collaborate in the development of more effective ways.

Within their own organizations, their leadership can...

- ... drive out fear with thoughtful recruitment and induction and consistent investment in educating staff to respect the dignity of those they assist and the importance of their role in assisting people to act and develop as contributing citizens.
- ... actively support the development of emotional intelligence among staff and the people and families the organization serves.

- ... recognize where good support is already happening in their organization and celebrate, share and learn from the on-going stories.
- ... encourage open communication and action to deal with conflicts and breakdowns in support with these directly involved supported to exercise as much responsibility as possible for repairing unacceptable situations and learning from errors and failures.
- ... provide opportunities to reflect on the ambiguities in the role and relationship of providing support and the ethics of authentic support.
- ... resist the temptations to defend against potential violations of external rules by multiplying internal rules and to react to individual troubles with policies that effect everyone.

The practices we advocate as creating the conditions for good support align with the policy objectives sought by personalisation and the UN Convention on the Rights of Disabled Persons. What we believe is necessary may demand substantial development in the way the social care system is administered but it is not a radical departure from the espoused objectives of existing policy.

Ideas for action



