Almost invisible – providing subtle support in community settings

Introduction

This article investigates some of the pitfalls and potential of supporting people on a one-to-one basis in their community. We discuss the importance of subtle support, and contrast it with more overt, visible and inappropriate ways to be with the person. Like respect, subtle support is hard to define in a sentence, although everyone we have spoken to knows exactly what it is, and can readily cite examples of success and failure.

Many years ago, Wolfensberger (1972, 1983) gave us some important concepts to consider when supporting disabled people in community locations. People at risk of being treated unfairly, he said, should avoid being seen in large groups as their negative labelling would be reinforced (he called this *deviancy amplification*). Specific neighbourhoods or interest groups should not be over-used, or their capacity to respond well to individuals needing support would be exhausted (*flooding*). Activities, possessions and clothes should, wherever possible, be *age appropriate*, to remind observers that adults are not children, and selected to convey the message that the person is of high status in this particular community (*cultural appropriateness*). Negatively valued characteristics should be minimised and positively valued elements enhanced in order to harness the impact of these status symbols (*the conservativism corollary)*.

People are now out in ordinary community locations, supported on a one-to-one basis, doing activities that they enjoy and that nondisabled people value too. But how do staff support the individual? Elsewhere, the first author has catalogued the strategies for engaging members of the public in offering support to disabled people (Bates, 2010), so here we confine our attention to subtle support by paid staff. Getting this right, right from the start, forms a secure foundation for the person to move into genuine engagement with other participants in the community, and so we hope this exploration will be particularly useful for newly appointed support workers, although more senior and well established staff and their managers may find it of interest too.

Bad support can harm

For some people, their only opportunity to connect with the community beyond the service occurs when staff accompany them. Providing one-to-one support in a public place is a subtle, delicate business which, if it goes wrong, can breed misconceptions, destroy reputations and shut down opportunities.

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Good support must be person centred, as what works for one person may not work for another, and so plans must clearly specify how the person wishes to be supported in each setting, how other participants will become involved, and how things will change over time. When done well, it enables some of the support to transfer from the worker to informal community members, and so the person merges into the general community and acquires friends. To do this,

- frontline staff need to develop skills in person-centred planning, community mapping, capacity building, subtle support and problem resolution
- advocates need to recognise the value as well as the hazards of engaging with the wider community, and
- employers need to support these activities in their confidentiality procedures, culture of risk management and opportunity support, and understanding of professional boundaries.

The plan needs to be available for both the person and the support worker to refer to, presented in an accessible format, and offer useful, practical, real-time guidance about what to do in specific circumstances.

Subtle support works for the person, sometimes leading by example and at other times going unnoticed. Community members don't routinely spot the SUPPORT WORKER and the PERSON THAT NEEDS HELP. Subtle support is the best chance the person has of being accepted in their community and being as independent as possible.

The cuts culture intensifies pressure on staff to be seen to be busy

Empowering the person is a step towards independence, but it can also feel like a step that diminishes the support role. In this time of austerity, both commissioners and providers are cutting costs by reducing contact hours and focusing on survival and safety rather than community participation. This can tempt support staff to try and secure their role by doing things *for* the person rather than developing their skills and supporting their independence and community participation.

Even in less austere climates frontline staff are held to account, sometimes by those who have little understanding of the nature of the work, and so staff can be tempted to misrepresent or even change their role. Instead of observing the person from a discrete distance, they may provide hands-on help so that they can be seen to be busy. Too much of this fosters the belief that "this person couldn't possibly get on without me" and meanwhile, the wider community learns from what it observes.

We fear that the positive change in services that has been accomplished over recent years from a culture of 'looking after' to promoting independence and community inclusion is at renewed risk of being undermined by the current pressures upon services. Moving from paid support to community networks and friendships is vital, scary and demands a change in thinking from everyone – individuals, families, workers, services and communities. Every learning disability organisation needs to

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keep a firm grip on inclusive values and practices via training, modelling, mentoring, supervision and monitoring.

Self directed support should not be staff or family directed

The power shift that occurs when directly provided services are transformed into self-directed support is to be welcomed, as it enables the person to take much more choice and control over where they go, what they do, who they engage with, who supports them and how it is done. However, we cannot assume that the system change will always reduce staff power and lead to a corresponding increase in empowerment for the person – instead, it may increase the power of staff or divert that power to relatives. Neither staff nor relatives will necessarily promote community roles and relationships, and, meanwhile, the system of controls that might regulate the quality of support remains patchy. Relentlessly focusing on the person themselves and what they consider makes a good life will help to overcome these hazards.

So we fear that, in combination, our three concerns about staff, the cuts culture and immature regulatory systems place one-to-one support in community settings under threat. We have to think ever more carefully about how to do it well. The following four situations illustrate different aspects of the support role in a community setting. Each section begins with an anonymised vignette, which we use to tease out some advice that we hope will assist new employees to think about their work, established staff to reflect on their practice and managers to consider how they ensure high quality interventions from staff who provide support in community settings.

Shopping with Clara and Dave[1]

> *In a supermarket recently Clara and Dave, who both use wheelchairs, were, discussing and selecting their favourite food and loading their own trolleys, assisted by two support staff. Then the staff seemed to get distracted from their support role by a conversation with each other that left out Clara and Dave. . "Great," I thought cynically, "support workers out again for their own selfish enjoyment of the shopping experience." Then the four of them seemed to come together as a whole group in an energetic conversation about the weekend's football match. When I passed by and made a comment to the seated people about the score , the whole group was all smiles.*

[1] We have used pseudonyms for all the people being supported to protect their confidentiality.

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Don’t judge staff too hastily

The group was doing what most shoppers do – wandering round the aisles and engaging in casual conversation. The absence of loud, clear, simple language - ‘DO YOU WANT BEANS?’ – did not mean that staff were ignoring Clara and Dave. Subtle support promoted Clara and Dave’s status as competent shoppers within their local community, resisting the accusation of negligence, as the staff deliberately held back and left Clara and Dave to fill their own trolleys - until one of them was invited to reach something from a high shelf. This is significant both for managers who may observe their staff at work in the community, and for managing the expectations of the general public.

Focus on how the individual is today.

Some people enjoy chatty banter even if they can’t respond verbally, whilst others would be miserable if support staff tried to engage them in this way. What is appropriate for the individual can also vary on a daily basis due to the effects of medication, seizures and mood.

Look for settings which carry the potential for friendships

Whilst it is vital for people to develop independent living skills, shop as independently as possible and establish a presence in the community, for most people living in cities, shops are not places where new friendships begin. If amenities such as cafes, supermarkets and parks form the majority of destinations, then it is unlikely that people who need support will build any new roles or relationships beyond the service, or get beyond a brief exchange of greetings.

In addition to using such amenities, support staff need to seek out places where friendships can form beyond the care system, where there are opportunities to do things that the person enjoys, where people attend regularly, share a common interest and everyone has a chance to contribute. It underlines the importance of paid work, learning and leisure environments as central elements of person-centred plans. Most importantly, it encourages support staff to focus on how they can introduce the person to others in the community setting, support emerging friendships and withdraw into the background or even out of the room entirely. Similarly, managers need to create a climate where staff feel able to take these steps and confident that they will be supported in their efforts to promote an independent life in the community for the people that they support.

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Singing with Chris

Two support workers came to a choir practice and sat at the back of the room. They spent most of the time talking and laughing under their breath, which made the choirmaster feel uncomfortable. Next time, I sat next to them and discovered they were encouraging Chris with their warmth, enthusiasm and laughter, but were the only people in the room who did not join in with the singing.

Choose the right person for that activity

In this situation, the support workers were too embarrassed to sing, and had avoided interaction with the choirmaster by sitting as far from him as possible. This wasted an opportunity to get involved in the session, relate to the person in charge and open up an opportunity for the person they were supporting to fully engage. Staff anxieties about their own musical abilities impeded their role as support staff.

Job applicants should be asked at interview if they are comfortable with engaging in specific activities, and the answers recorded, so that difficulties do not arise later on. Where specific activities have been identified, this can be built into the job description or person specification. Once in the role, staff have a responsibility to be open to new ideas and try new activities in support of the person – this can sometimes lead to the discovery of new and rewarding activities that they didn't anticipate enjoying.

But this is tricky. Some workers are confident, and extrovert and always busy, while others prefer to live quietly and would have a genuine problem with an activity such as singing in public. As a result, 'fussy' staff only do things that they like, 'favoured' staff are repeatedly selected for treats and 'flexible' staff end up with all the rest. Workers who genuinely dislike singing should make sure that their discomfort does not deprive the person of the opportunity, either by going along and joining in anyway, or, where possible, by initiating a swap of shifts with a colleague.

Perhaps the best solution is to find or recruit a member of staff who is already passionate about the activity and well connected to that particular community of interest and allocate them to the support role. This is most likely to happen if the person being supported knows exactly what they want to do in advance and then interviews, selects and employs their own support worker. Then the employee can model enthusiastic participation to the person they are supporting. However, care is needed here too, as the worker may become so engrossed in the activity that they neglect their support role, and the person may end up going along with the activity to please the worker rather than out of personal interest.

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Find out about the group's rules

Many choirs, drama groups and other community activities have a 'no audience' rule for their rehearsals and only allow people to watch at specific times. So by not enrolling properly and joining in with the choir, staff had not only identified themselves as support workers, but had failed to understand or respect the ethos of the choir. Furthermore, they portrayed Chris as incapable and dependent on their presence and other choristers as unable to offer appropriate support.

Alternative ways to offer support have consequences too. Sitting outside the room abandons the person. Attending the first few sessions and gradually tapering away models poor commitment to other choir members. Behaving like an ordinary member when you are present simply to support the person risks being seen to be dishonest.

Resist fear

Sometimes it is simply a personal challenge to get over the fear – a simple decision to sing with gusto rather than sit at the back, to face up to the possibility that there may be a time when we are not needed. Staff can feel afraid of letting go or afraid of what others think, whether that is the person they support, their work colleague or other choristers.

Sometimes employers create risk-averse regulations which inhibit optimistic approaches to independence and inclusion. The team climate can become pessimistic, encouraging everyone to believe that the person will be unable to cope with more independence or community participation. It can be easiest to assume that other staff know best and is hard for an individual worker to resist their fear of others and challenge negative assumptions, but it is what the job is all about.

Instead, managers need to foster a culture where it is acceptable for people to take positive risks and be independent. Sometimes this means reducing paid support and relying on friends and natural supports. Staff may need training to help them support the person to build strong community links. A circle of support may share the decision and mitigate the fear that someone may be blamed if something goes wrong.

Studying with Sarah

Sarah attends a lot of college courses. She lacks confidence at the beginning, so a support worker usually goes along to the first session with her, where Sarah asks her own questions, completes paperwork and introduces herself

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to the tutor and other new students. Sarah likes having the worker present to be a familiar face, and offer reassurance that she did well, met nice people and should go again. One worker who has supported Sarah in this way felt redundant and is now encouraging her to register independently next time, while another worker is responding to Sarah's own request for support.

Consider friends

Sarah simply wanted a familiar face around, so couldn't a friend do that? Sometimes the worker is offering subtle, low key but highly skilled support, but at other times, this role could easily be carried out by a friend, relative or another student. Inviting such people in and encouraging them to provide appropriate support may demand that the service thinks again about how to balance safeguarding and inclusion.

Avoid smothering

After many years in contact with the service, Sarah now only feels safe when staff are within sight. Sometimes staff collude with such low expectations and so delay the development of independence. Providing too much support in this way harms the person, lowers expectations and damages the attitude of community members.

Negotiate before you go out

Sometimes people feel independent, but actually need support in order to keep everyone safe, while others ask for help, but do not really need it. Support is almost invisible when these negotiations occur beforehand so that people know what help is on offer and what they are expected to do for themselves. Prior agreement with Sarah to withdraw support over time allowed her to gradually get used to relying less on her worker, and avoided disagreements whilst at college.

Reduce reliance on support

It is difficult to get the balance between supporting someone too much to the detriment of their independence, and too little, causing the opportunity to fail. Careful planning is needed with the person in charge of the community setting to stimulate the formation of networks of informal support and provide appropriate resources so that the person can succeed. This planning will include:

- Consideration of confidentiality and disclosure arrangements in order to keep everyone safe and to allow Sarah to disclose things about herself at her own pace, in the same way as others would in a social situation
- How some support activities will be taken over by other students, the tutor or learning assistants, so it does not appear that support workers are losing interest or failing in their responsibilities.

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- How the support worker's contribution will gradually reduce as the person develops competence
- Arrangements for identifying issues of concern as early as possible so that difficulties can be resolved rather than allowing the arrangement to break down.

Dancing with Mark and Dave

Mark and Dave love going to the night club and their support worker takes them every few weeks. One night when I saw them there, they were the only people in the place wearing suits. I asked, "what's the special occasion?" and the support worker, in a little black dress, interrupted to explain that she made sure they wore their 'best clothes' when out clubbing so people don't assume they can't afford a suit. Having said that, she returned to her conversation with the guy on the next table.

Wear the right gear

Both individuals and their support staff need the right clothes and accessories in the community. The support worker may need to make time to change if she has a varied day, or consider which outfit is more appropriate – surely it is more important to fit in at the night club and risk standing out at the staff meeting? Community members in the night club and elsewhere will easily spot the telltale work badge or official diary that mark out the paid worker. Disabled people too, are judged by their clothing, and the support worker understood this, perhaps even applying Wolfensberger's 'conservativism corollary'; in a naïve way by seeking to enhance Mark and Dave's status in the community through showing off their best clothes. 'Best' is, of course, contextually defined, and efforts to enhance their status in the community in this way would require some seriously trendy clothes.

Avoid over control

Overpowering, loud and intrusive support workers can be perceived as bullies, prompting the person they are supporting to choose compliance rather than create a scene. Such workers bring large, confident personalities to their role and can sometimes be heard (even in the noisy night club) advising the person about the toilet or their dance steps.

Such sustained intrusion and embarrassment can be almost unbearable, especially when the person is unable to voice their distress or is not taken seriously. People suffering such sustained bullying may turn in on themselves and feel completely

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unable to share their feelings with anyone else. Support workers who answer for the individual reduce opportunities for both the person and community members to get to know one another.

The very opposite can happen too. If the person being supported is loud, bubbly and likes to be noticed, the support worker may be embarrassed and constantly tell them to be quiet or pretend not to know them. This can be very demoralising for the individual and will make them stand out even more. Community members may copy the reaction of the support worker, damping down exuberance rather than enjoying it.

Choose to enjoy being with the person

The support worker preferred the people on the next table to Mark and Dave. If, on the other hand, the support worker is happy and comfortable with the person, other people will also want to be with them. The person also has to like the support worker otherwise they may be uncomfortable and outsiders may misconstrue this as the person being difficult or antisocial. This will affect how they are accepted in their community.

Work as a team

On its own, genuine care may not be enough to ensure good support. Training in person centred approaches, community inclusion and how to support someone in the community is needed. This may require closer working relationships between families, social workers, therapists and support workers, with the person in the centre, so that the support worker is clear what they are doing is valued by other team members. The whole team needs to be working together and monitoring the effectiveness of what they are doing.

Conclusion

This paper has explored a number of key components of subtle support. These include:

- doing less rather than more, holding back so that the person tackles practical tasks and social relationships themselves whenever possible
- supporting the development of informal relationships beyond the service, and backing this up with policies and an organisational culture that support workers in this task

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- whenever possible, being a full participant in the community activity rather than a detached observer
- careful planning so that, over time, the person becomes increasingly independent and socially engaged in the community setting
- enjoying the company of the person and seeing them become more connected to their chosen community.

Subtle support that allows a person to be become more independent, less reliant on services and more socially included is a complex business. In order to overcome the many pitfalls of supporting someone in the community, staff need training, time to discuss their experiences and recognition that it is an ongoing challenge with no easy solutions. But it is vital if people are to be fully included in their community.

> *You wouldn't even notice Robert's support worker. He takes part in the gym session, either helping run it, supporting other people, or just joining in and then inviting Robert to join in as well. When Robert needs support, the worker might help, or he may hold back so that another member of the group steps forward to assist. He doesn't worry if Robert wanders off round the room, and when others raise concerns, he calmly says 'he's fine' and distracts the worried person.*
>
> *When Robert decides it is time to go somewhere else, his support worker goes with him, perhaps on the pretext of making a cup of tea, or very subtly at a discrete distance. He will then guide Robert back when he is ready and carry on with the session like they had never been away. The group are learning from the support worker about how best to support Robert and allow him the independence and freedom to take part in the session in the way that he chooses.*

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