

# The changing of the guard: Groupwork with people who have intellectual disabilities

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**Abstract:** *This paper considers the impact of service systems on group activities. It describes an inter-professional groupwork project facilitated by a social worker and a community nurse. The project provided an emancipatory experience for a group of adults who had intellectual disabilities. The group was charged with the task of reviewing and updating the recruitment and interview processes used by a 'Learning Disability Partnership Board', when employing new support workers.*

*The paper begins with a brief history of intellectual disability and provides a context to the underpinning philosophical belief that people should be encouraged and supported to inhabit valued social roles no matter what disability they may have. It then identifies the ways in which the sponsoring health, education and social care services impacted on the creation and development of a groupwork project. It might have been expected that the nature of the intellectual disability would have been the major influence on group process. However the paper reveals that organisational constraints had a significant impact on group functioning. Issues including, staffing budgets and transport contracts impacted on group process and function.*

*The results of the project show how, with adequate support, people with intellectual disability can make important decisions that have long-reaching impacts on the services.*

**Key words:** *Intellectual/learning disability; values; inter-professional; emancipatory; support, organisations; groupwork; groups*

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## Introduction

Imagine for a moment that there is a 'Ministry of Fair-Play'. The Ministry has a remit to bring social justice to marginalised groups in society. The Ministry has decided that it must free all people from the tyranny of unelected oppressors and has devised a programme to ensure that individuals of all colour, creed, gender and political persuasion must have equal rights.

The Ministry toils over decades to make this dream a reality. Just as it thinks that it is close to achieving its goal it realises that there is one particular area where a group is still living a 'closely guarded' life. Members of this group have no criminal background and no physical or mental health problems that would warrant close monitoring.

It is decided to send a deputation to meet members of the group to help them to 'review' their situation. However, although Ministry representatives think that they understand the language used by the group, they are aware of the following:

- The group uses several dialects so the deputation can't always be sure that they understand what the locals are saying as some words are used interchangeably; only 15% of the group can read or write. After the 'review' the deputation is to oversee a power sharing agreement between group members and their guards.
- 95% of group members are guarded in their homes and work places; some have a guard with them 24 hours a day, every day.
- The situation has been the same for so long that some group members consider that some of the guards are their friends; this is especially true for those group members who have no other contact with the outside world.
- Some group members dislike their guards but can never get away from them.
- The guards have been told by the UN that they have to let the locals have more of a say in their own lives ... including choosing who guards them.

The preceding scenario may seem a little far-fetched; it was, however, very close to reality for a group of intellectually disabled adults that came together to learn how to choose their own support staff or 'guards'. The

following paper will discuss some of the stages that the group went through as they began to understand that they had choices in who they should allow to work with them. It will also discuss the effect of external service systems upon the internal workings of the group.

## **Literature review**

### **Terminology**

Although the term learning disability is still widely used in the UK to describe people who have an IQ of less than 70 (World Health Organisation-International Classification of Diseases, ICD-10) it is also frequently used when referring to conditions such as dyslexia and dyspraxia.

The term intellectual disability (ID) is preferred in Australia and some Scandinavian countries, yet Mental Retardation and Developmental Disability are still commonly used in the USA. Russell et al (2005) provide a persuasive argument for the international adoption of the term 'intellectual disability', arguing that it has been gaining currency throughout the last decade and has yet to be 'stigmatised' (p.191) and 'medicalized'(p.192). This will be the term used throughout this paper wherever possible; however the term learning disability will also be used in this paper when discussing legal frameworks and terminology used in the early years of the 21st century.

### **IQ: Developing a fiscal measure of disability**

In Western societies people with intellectual disability have, in the main, led unremarkable lives alongside other members of their communities. The situation changed gradually during the industrial revolution when they became viewed as economically burdensome, as many were unable to keep up with the machinery that began to dominate working lives. (Race, 2002; Williams, 2006).

IQ testing became an accepted tool for measuring whether or not an individual was capable of work. If deemed incapable due to low IQ the person would be cared for by the state. Although IQ testing is often undertaken as part of a more comprehensive range of testing including

tools such as the Weschler adaptive behaviour test - a measure of social functioning- it is still the IQ score that determines whether or not a person is defined as intellectually disabled.

Although the measurement of IQ has long been used to categorise people, for purposes of schooling and access to other state support, the attainment level has not always been 70. For example in the USA up until 1963 any person with an IQ of less than 85 was deemed to be intellectually disabled. The lowering of the threshold was prompted largely as a result of fiscal policy. The reduction from 85 to 70 meant that instead of 16% of American citizens being eligible for state aid only 3% remained eligible. Another 'coincidental benefit' of the change was that thousands of people who had an IQ of between 70 and 85 became eligible for conscription during the Vietnam War (Edgerton, 1993).

Thus there is a clear link between productivity, cost and value of an intellectually disabled person. The notion of putting a value on a person's life is not a new one; however the notion of trying to improve how other people view a life is relatively recent.

#### **Social Role Valorization:**

##### **Developing a valuing approach towards intellectual disability**

In the 1960s an international movement developed, aimed at improving the lives of intellectually disabled people. The movement, largely led by academics, spread from the Scandinavian countries of Denmark, Sweden and Norway to the UK, Australia, Canada, the USA and New Zealand. It was predicated on what became known as the 'principles of normalisation', its aims were to 'make available to the mentally retarded such patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream society'. (Nirje, 1969).

These principles were later developed by Wolf Wolfensberger and John O'Brien and known variously as Social Role Valorization (SRV) and Ordinary Life Principles. Although the movement has largely been consigned to the pages of history in most countries it can be argued that the principles are embedded into the legislative processes of those listed in the previous paragraph.

In 2001 the UK set out its vision for people with ID. *Valuing People* (2001) contained four principles; Rights, Independence, Choice, and

Inclusion, closely linked to the principles of a valued yet ordinary life – a life that would not be found wanting when compared to that of a non-disabled contemporary. These were accompanied by the requirement that local authorities form ‘Partnership Boards’ comprising such local statutory, independent and voluntary agencies as were providing support services for people with ID. These included health, social care, education and housing services. The boards were charged with promoting inter-professional approaches to ensure that people with ID should at last be able to enjoy the patterns of everyday living enjoyed by their fellow citizens that Nirje had hoped for some forty years earlier.

### **Involving people with ID in groupwork**

The groupwork canon contains relatively little literature published on groupwork with people who have ID. This is partly due to a somewhat overly paternalistic stance taken by some research ethics boards (Walmsley, 1990; Hays et al, 2003; McClimens, 2004). Such boards recognise the potential vulnerability of people with ID without seeing the emancipatory value of supporting them to develop as researcher participants and indeed researchers in their own right.

However, the body of literature has grown in the last decade and there is now ample research to show that people with ID can, with support, contribute to, and in some instances lead groups, and make defensible decisions in their own right. (Chia, 1995; Walmsley, 1997; Holman, 1999; Barnes, 2003; Rodgers et al, 2004).

Major funding bodies such as the Joseph Rowntree Foundation and the Norah Fry Research Centre seek to redress the balance of research being ‘done on’ to that of ‘being done by or with’ people who have ID, making it a requirement of the research grant that research includes people with ID as active participants or co-researchers; or at the very least that research proposals should be clear about the importance placed upon the proposed research by the relevant service user group. Ward and Simons (1998) and Kiernan (2003) also stress the importance of involving service users in the formulation of a research question and the design of projects rather than imposing the researcher’s own ideas upon them.

Such work that does exist places importance on understanding the communication preferences and support needs of individuals

in the group. Many techniques have been developed for facilitating communication such as using pictures, technical aids and multiple-choice questionnaires. However, there is evidence to suggest that these methods are in danger of being used inappropriately and that many people still prefer the support of a person who is trusted by them, who knows them well and has had time to learn how to interpret their methods of communication (see Cardore, 1999; Holman, 1999; Stancliffe & Abery, 1997; Rodgers et al, 2004). The importance of this knowledge and trust will be discussed later in this paper.

Little research appears to have been undertaken on the impact of wider social and institutional networks on the ability of people who have intellectual disability to function in groups. The following paper will discuss how 'service' areas significantly affected the functioning of a groupwork experience with people who had ID.

## **Background to the project**

The Choosing Staff project was undertaken following a series of focus group meetings. The focus group agreed that review and amendment of recruitment procedures would be a useful starting point if services were going to successfully encourage inter-professional working in front-line services. As such, the Choosing Staff Group (CSG) project was set up. It was to focus on the development of new recruitment and selection policies and procedures. These procedures would be adopted by all agencies when recruiting new support workers to work in their agencies. The entire process of recruitment from designing the advertisement to interviewing candidates was reviewed by the group of intellectually disabled adults. The group then amended job descriptions, person specifications and designed interview questions, reflecting their own ideas of what made a good support worker.

It is important to note that most of the agencies represented on the Partnership Board already included intellectually disabled people on their recruitment panels, but these people were generally invited onto a panel with no prior training. Given the relative power differences between the person with intellectual disability and the other people on the panels it is difficult to say if the person with ID felt able to really exercise choice, or merely confirm the choice of the other panel

members. Williamson (1993) and Herd and Stalker (1996) agree that while the final decision to appoint must rest with the employer, the best decisions are made following consultation with a pool of former, current and potential service users. They go on to advise that preparation and accessible information are key aspects of meaningful service user involvement.

The CSG project was based on the Townsley et al (1997) training pack which was specifically designed to support intellectually disabled people wanting to recruit their own staff. The pack provides guidance for all stages of the process. It recommends that the process can be completed over a three day training programme, however this paper will discuss a thirteen week project (twelve sessions and a 'half term' break) designed to meet the needs of a diverse group, while fitting in with their service requirements. The change from three consecutive days to twelve weekly sessions was made at the suggestion of Mohommed and Jack, two intellectually disabled members of a focus group who felt that three days would be too intense and tiring for some of their contemporaries. Mohommed and Jack attended a college for people with ID. The college supported the idea of the group but could not support students to attend meetings during the half term break; thus began the intertwining of group and service that was to impact on the functioning of the group throughout its existence.

It is important to note that in addition to their intellectual disability some of the members of the Choosing Staff Group (CSG) lived with the additional challenges of physical disabilities or mental illness.

## **Group membership**

CSG members came from, but did not claim representation of, a variety of services. Mohommed<sup>1</sup> and Jack (both 17 years old) came from college and still lived at home with their parents. Jack had cerebral palsy. This affected his speech and meant that he had to use an adapted wheelchair. They were supported throughout the course by Norma, a classroom assistant.

Sally (24) lived in a local authority supported tenancy, with people that she did not like, and she was said to regularly challenge services. She was accompanied by a different support worker almost every week.

Mal (22) also had cerebral palsy and used a wheelchair. She lived with her parents but wanted to move in with her intellectually able boyfriend. She was engaged in a constant battle with parents and service providers as she sought 'permission' to settle in a life outside services. Derek (32) lived with his parents and refused to enter services because he found them restrictive and lacking in imagination, he attended a citizens' advocacy group with Mal. Mike (38) also attended the advocacy group and had used a number of social and health care networks. At the time of the group he was engaged in a complaint against service providers because he felt that no-one was taking his request to live independently seriously. Alice, an intellectually able volunteer who supported the activities of the advocacy group, supported all three.

Tom (71) had lived his life in a long stay hospital moving into a supported tenancy when the hospital closed. He spent his days attending a day centre based in the grounds of his old hospital. Linda (46) also attended the hospital day centre. She lived with her parents and her mental health problems had led her into serious confrontations with others; she too had lived for many years with a label of 'challenging behaviour'.

The group was facilitated by a social work trained staff development manager and a community nurse whose specialism was in the branch of learning disability nursing. Although the Choosing Staff project was undertaken as a service development initiative it was analysed and reported as part of an academic research project and as such was subject to the relevant ethical approval processes.

## **Offering the Group**

Doel and Sawdon (1999) identified the following process of group formation:

*Engagement → Linking → Induction → Mediation*

It was clear from the outset that trying to use this model would be somewhat over optimistic. Engaging the interest of people was fairly easy. What proved to be much more difficult was securing support for people to attend.



There was no requirement for people to bring a support worker with them; however, facilitators had secured agreements from service managers that they would provide support for anyone who wanted to attend, if the person felt that it would be beneficial. The support, being readily offered in the planning stage, became much more difficult to secure when the project became a reality. The facilitators had to return to managers several times to negotiate adequate levels of support.

This was particularly difficult for the statutory social care service, as it was going through a period of immense change, facing staff shortages and changes in key management personnel. A pattern emerged whereby individuals expressed curiosity about the project. This curiosity was generally prompted by workers in the services who had seen posters advertising the group; or those who knew members of the focus group. The individuals and workers linked together to approach the facilitators, who in turn negotiated with managers so that the workers could be released from other duties to attend the group. Although several people from the service expressed an interest in joining the group only Sally was able to attract regular support. A pattern of formation emerged that was different from the pattern identified by Doel and Sawdon (1999). It was:

*Curiosity → Linking → Negotiation → Engagement → Induction → Mediation*

## **Group processes and functioning**

Eventually the group was able to meet together for its introductory session. The session started as much groupwork does, with an icebreaker. Using pictures and discussions, individuals set about the task of getting to know each other. The room was set out in the familiar horseshoe style, allowing for everyone to move about and speak to each other.

The session worked well, in some ways it was easier to engage this group than a group whose members are 'sent' as part of their training or therapy. CSG participants were generally compliant; being used to 'doing as they are told' by those in authority they readily participated in the task.

Once the ice had been broken the group was introduced to the task of understanding what a job is. It had been anticipated that people

would readily understand this task and, indeed participants understood jobs such as police officer, gardener and teacher but they had little comprehension of the job of support worker. Those who lived at home were surprised to learn that if they moved out of the family home they might be subjected to a tenancy model whereby people who were not their parents would still be 'in charge' of their daily routines. That, in effect, they would be guarded.

Those familiar with the tenancy model, adopted by social and healthcare services, were surprised that people were actually paid a wage to support them. After the initial confusion at the revelation that people did not support them because they were their friends, participants began to ask searching questions. Tom observed that if people were trained and paid... 'then why are half of 'em so b\*\*\*\*y useless?'. The group quickly agreed that if money was being spent on their support then it should be spent on people who did the job properly. They were all keen to come back the following week to get started on the task of writing out person specifications, so that they could get more of the good staff and make sure that no more 'bad ones' supported them.

In week two the CSG followed anticipated processes of group development with facilitators recognising patterns of 'storming' (Tuckman, 1965, cited in Trevithick, 2005) and uncertainty-exploration (Northen and Kurland, 2001). Participants continued to walk around the room as they had in the initial 'getting to know you stage' and the session quickly lost focus. This loss of focus caused Sally and Mike to become distressed and they asked, at different times, if they could leave the room in what could be considered to be deployment of their usual defence mechanisms (Bion, 1961). 'Time out' was a method of behaviour modification familiar to both participants and they adopted this approach to avoid getting into difficult discussions about sensitive topics.

It was obvious that years of schooling in anger management by various institutions had left Sally and Mike with the self knowledge about their own anger and how to contain it but without recourse to challenge others. They automatically assumed that their opinions would be overruled by the dominant opinions of group facilitators. This led to a conundrum for the facilitators who had striven for the project to be empowering for participants. Facilitators had tried to weave the values of self-directed, emancipatory groupwork into the whole process

(Mullender & Ward, 1991; Preston-Shoot, 1987; Ward & Boeck, 2000; Edge, 2001; Kevan, 2003) and began to doubt that it would be truly empowering if participants censored themselves rather than speaking up in the group.

Previous experience of supporting people with intellectual disabilities led the facilitators to believe that perhaps the participants might feel safer and more able to challenge others if they changed the layout of the room and provided physical barriers between participants. They arranged the chairs around a large central table from week three onwards ensuring that there was a choice of spaces for Mohammed and Mal.

This simple change worked, together with explicit permission from the facilitators that disagreement was OK. The group then began to function much more effectively. However, by session nine facilitators were actively suggesting where some of the participants should be seated, in order to minimise eye contact and thus prevent negative interactions, especially between Sally and Derek.

Group cohesion was gained and the participants worked together well. However, on returning from the mid-point break Jack expressed his disappointment that the group did not seem to be 'getting anywhere'. His statement and the subsequent discussion prompted a rush of activity resulting in the finalisation of the job description and person specification. The group also drafted a mission statement for the Partnership Board, which was subsequently adopted and included in all advertisements. This rush of activity appears to conform closely to Gersick's (1988) two stage model of punctuated development. Gersick noted that groups conform to a pattern of two phases of relative inertia punctuated by a time of rapid change. This 'punctuated equilibrium' cited in Tyson (1998, p.11) occurs roughly halfway through the life of a group as it realises that it has to complete its task.

The group continued to function much as any other would; it completed its task and made recommendations to the Partnership Board. Within six months Jack and Mohammed were involved in drawing up a job description and person specification for a Deputy Head of their college. They both participated in the interviews and their comments about candidates and recommendations for appointment matched those of other interview panel members. The successful candidate commented after her appointment that she had been successful in two interviews

for similar jobs that week; but she had chosen to work with the college because she felt that they put their principles into practice by clearly involving students in high level decision making.

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The preceding section has provided a snapshot of some of the achievements of the group. It has tried to show how a group of intellectually disabled people came together to make far reaching changes to local policy and practice. It has discussed some aspects of groupwork and shown how general groupwork principles can and do apply to this client group.

The following part of the paper will discuss how group processes were influenced by the organisations that commissioned the project and sponsored its participants.

## **Reality versus rhetoric: The influence of services on group process**

### **The Local Authority Social Care Service**

This service was undergoing major changes, as previously discussed. These changes impacted on the group particularly strongly for Sally. Although senior managers were verbally supportive and committed funds to facilitate the group they were unable to guarantee a regular support worker to accompany Sally and she was often accompanied by a casual worker from a bank of temporary staff.

This meant that the intended closed group became partially opened up, due to the attendance of a new person each week. The benefits of a closed group include a group understanding of the tasks required, the ability to make progress from week to week, without having to review previous work in great detail and mutual recognition of each other as members of the group. Having a new participant each week meant disruption for all participants. Would the person fit in? Would they understand where the group was up to? Would they agree with decisions already taken and if not, should the group change in recognition of a new influence?

Sally began to sit slightly apart from other group members; she

spent a lot of time explaining things to her support worker, who more often than not appeared to be there for the overtime rather than any commitment to Sally or the group. Only once did her support worker appear to have helped Sally to prepare for the group. On other occasions workers seemed to be at best, trying to fit in but wondering what was going on or, at worst, openly hostile. On one occasion the worker seemed to be threatened by the notion of service user empowerment, adopting a confrontational and disruptive approach. Participants were initially cowed by this approach until Jack, supported by Derek, suggested that he could either help Sally like he was supposed to or he could wait outside because he was stopping them from getting on.

This was a turning point in the group. The two young men approached one of the facilitators at the end of the session and asked if a complaint could be made about the type of support that Sally was receiving. Sally felt that she could not speak up for herself as she might be accused of causing trouble. This was the beginning of group identity and of transferring learning from the task into the resolution of problems of everyday life. It was challenging because so many things were still wrong with Sally's home life, yet it was rewarding because it showed the power of group learning and a development of mutual support.

On a positive note, the worker's manager took the complaint seriously and changes were made to the training of casual workers following this complaint.

### **Health Service**

The support provided by the health-led day centre was valued by Tom and Linda. They had the same support worker, Janice, every week and because she worked in the day centre every day she was able to help them with their homework tasks back in the centre. They were able to discuss issues raised in the group with other service users and share learning between the group and the service.

A less positive aspect of support from this service was the rigidity of structure imposed on the group. The service did not replace Janice in the centre, so it was, in effect under staffed during her absence. This meant that the group always had to end promptly at noon so that she could be back at the centre for lunch and, more importantly, administration of medication between 12.30 and 1.00pm.

Another problem was lack of flexibility at the beginning of the day because the participants had to be bussed in to the day-centre before attending the group. Linda's bus passed the venue that hosted the CSG on her way to the centre but the company's insurance did not allow for her to alight before the contracted destination.

### **Specialist Further Education College**

This service provided excellent support for Mohammed and Jack. Norma supported them almost every week, the one exception being when she was ill, but her replacement was fully briefed. Although the CSG timetable was planned to fit in with the college requirements this was the only real imposition from that service. Learning passed from the CSG to the college providing learning opportunities for other students and aspects of our syllabus became integrated into theirs. For example, as the CSG discussed confidentiality and decision making, so did the college.

It was disappointing to note that although the college was nominated for a prize for their work in supporting Jack and Mohammed in a radical approach to recruitment and selection of staff, they omitted to mention the fact that the CSG had been an inter-professional project. It was apparent that the competition embedded into the education system, but still in its infancy in the other services, meant that any developments had to be seen to have originated there, rather than with partner agencies. Happily, Mohammed and Jack were jointly awarded student of the year certificates.

### **Achievements and endings**

Although it started with a fairly simple agenda, the CSG became much more than a training group for the participants. It straddled the dual purposes of education through action learning and social development. Cohen (2003) suggests that social action groups can provide opportunities for personal change in participants and this was certainly true for everyone who participated in the project.

The ending was managed in a celebratory way with a meal and the presentation of certificates. Everyone was given the opportunity to say

what they had achieved during their time in the group. Some of the responses were predictable, others showed that the group had achieved much more than intended. Mike shared his new found confidence with the group saying 'I feel I could say words, not just here, to other people and they might listen to me'. Two weeks after the group finished he contacted one of the facilitators to say that he was moving to better accommodation.

Linda said 'I liked the equal opportunities pictures; I learned not to make my mind up too soon'. This was a huge statement for her as she had tended to make quick decisions and forceful contributions in the early stages of the group. However, as time passed, she learnt that it was acceptable not to have an opinion straight away. She realised that she could ask questions before deciding on her response. She continued to practise these skills away from the group, reporting that, although she still felt anxious when things went wrong, she felt more able to ask why and seek resolution rather than to become angry.

## **Conclusion**

This paper has explored the processes of groupwork in relation to people who have intellectual disabilities. It has demonstrated that groupwork can be an effective and enjoyable tool for helping people to gain knowledge and develop skills. It has also discussed some of the ambiguities inherent in service systems. On one hand they seek to empower and work in partnership with people who are eligible to use their services; yet some still struggle to facilitate methods of empowerment.

This paper supports Read and Papakosta-Harvey's findings (2004, p.206) that 'skills and strategies used by group facilitators are crucial in enabling individuals to actively engage with fellow participants in a constructive way'. In the case of the CSG, mutual respect between the group and its facilitators enabled all to develop greater understanding, not only of recruitment and selection but of what is really important for services to know about the people who use them. Messages received from the group directly impacted upon service providers and there began to be a shift of power from 'the guards' to the group.

## Note

1. Throughout this article, names have been changed to protect anonymity.

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