

Saying no to the staff: an analysis of refusals in a home for people with severe communication difficulties

Abstract

People with severe communication difficulties may attempt to exercise control over their lives by refusing an activity proposed by supporters. We detail examples in which such refusals are treated by service staff as a temporary reluctance, warranting further attempts to persuade the individual to cooperate. We identify the following conversational (and bodily) practices by which staff achieve their institutional ends: appreciating resident's behaviour as something other than refusal; formulating the invitation again in a no-blame format; minimising the task required; escalating the invitation to a request and an order; moving the person bodily; and positively glossing the proceedings. Dealing with refusals illustrates the dilemma faced by institutional personnel in accepting choices which might disrupt the efficient management of the service.

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Recent government proposals on social exclusion and disability in the United Kingdom stress that social care services should promote choice, control and empowerment (e.g. Department of Health, 2005; HM Government, 2005; Prime Minister's Strategy Unit, 2005; Social Exclusion Unit, 2005). These concerns accord with the notion of person-centred support based on work emanating from the U.S.A. (e.g. O'Brian & Lovett, 1993; O'Brien & Lyle O'Brien, 1988).

However, policy-makers also recognize that there are barriers to the promotion of empowerment in services. For example, the recent UK government report *Improving the Life Chances of Disabled People* (Prime Minister's Strategy Unit, 2005) discusses two main barriers: supports are often not fitted to the individual, rather disabled people are expected to fit into existing services (for examples see Beamer & Brooks, 2001); and services tend to focus on incapacity, inability and risk, with the result that dependency is created. Indeed, this report identifies a 'culture of care and dependency' (p73) in health and social care services in the UK, in which those with 'significant cognitive and/or communication impairments are particularly at risk of being denied choice and control in their lives' (p78; see Hatton et al, 2004; Kishi, Teelucksingh, Zollers, Park-Lee & Meyer, 1988, Stancliffe, Abery & Smith, 2000, for further evidence).

The problems in translating policy goals of choice and autonomy into practice for people with learning difficulties have been discussed by many commentators (e.g. Beamer & Brookes, 2001; Dowson, 1997; Edge, 2001; Guess, Benson & Siegel-Causey, 1985; Harris, 2003; Jenkinson, 1993; Jenkinson et al, 1992; Kishi et al, 1988; Lovett, 1996; Stalker & Harris, 1998). Even with changes in the ways services are commissioned and the types of services available, without a sensitive workforce these broader values will not be achieved (Department of Health, 2005; Social Exclusion Unit, 2005). This is particularly the case for those with multiple, complex support needs, who reports have identified as benefiting least from current policy initiatives in the UK (HM Government, 2005; Learning Disability Task Force, 2004).

Choice and control are issues that arise in the way people talk to each other, in which utterances are taken up and which are ignored, in how and what options are offered, in how preferences are expressed, how information is presented, how spaces are opened up for people to express preferences and how spaces are shut down. While

this applies to all people with intellectual disabilities, the expression and recognition of preferences in everyday interactions are particularly important for people with communication difficulties, who may have restricted access to other sites in which they might exercise control over their lives. However, detailed examination of how this is done in recorded interaction between staff and people with intellectual disabilities is rare (for examples of such research, see McConkey, Morris and Purcell, 1999, and *Authors reference*). When it comes to interaction between staff and people with severe communication difficulties, there is, so far as we know, no published analysis of video records of routine care-home encounters (although see Houghton, Bronicki & Guess, 1987, for a classroom observational study).

This paper seeks to remedy the lack by examining, in detail, one crucial aspect of choice in a residential service setting: the person's right to refuse. Refusing a member of staff's invitation or instruction is a particularly sensitive issue, shot through with difficulties for both sides. Its sensitivities make it particularly vulnerable to contamination by the research method chosen. How staff respond to residents' refusals is not likely to be easily captured in a questionnaire survey, nor will more qualitative forms of investigation - for example, interviews with staff, or questions to self-advocacy groups with residents - necessarily yield the detail we want. Retrospective accounts are undermined by memory loss, the desire to please the interviewer, and a concern to tell a coherent (but possibly inaccurate) story.

The most reliable data to study (especially when the events are complex) are video records, informed by ethnographic background. Analysis of video-recorded details of the actual exchange between staff member and resident is, we argue, necessary to bring out the particular practices that are used (especially on the staff's side) to manage the balance between respecting the resident's rights, on the one hand, and pursuing the institution's legitimate goals on the other.

Method

Overview

We shall present a qualitative analysis of episodes of residents in a social care home declining to take part in an activity put to them by staff. Because the interactions are complex, and the analysis detailed, considerations of space limit us to two episodes that illustrate the wider theme. In each case the reader will see how a resident initially declines to take part in an activity, then how the staff treat this

refusal, pursue compliance, bring the episode to a conclusion, and put a positive gloss on proceedings.

Data

The examples presented here come from an ethnographic project which took place in three residential services for people with intellectual disabilities. These three services were located within an NHS Care Trust in the South of England. Over the course of nine months, a researcher (one of this article's authors, CW) collected video and audio recordings, and ethnographic field notes of everyday interactions in these homes. The examples here were taken from one home for people with high support needs in which even the most communicatively able residents only have recourse to vocabularies of a small number of intelligible words or signs. The residents are therefore highly reliant on members of staff to interpret and act on the few words, signs, sounds, gestures or facial expressions that they may use to express themselves or make their needs known. Further, many of the residents are reliant on staff for aspects of intimate care, such as the promotion of continence. Thus, members of staff are institutionally compelled by their 'duty of care' to pursue and promote particular practices and activities at particular times of the day.

The names of all residents and members of staff have been replaced with pseudonyms, and any other information that might lead to their identification has been changed.

Method

Our approach involves looking in detail at what happens in these situations, in particular how each person designs their utterances, and how those utterances develop in sequence. In this respect our approach is broadly informed by Conversation Analysis (for an overview of Conversation Analysis see Hutchby and Wooffitt, 1998, and for a comparison with other forms of discourse analysis, Wooffitt, 2005). Within the field of research on intellectual disability, Conversation Analysis (henceforth, CA) has been used to study the communicative competence of people with intellectual disabilities (e.g. Wootton, 1989), the practices of clinical assessment and service evaluation (e.g. *Authors refs*), the management of service-user meetings (e.g. *Authors refs*), the interactional production of 'incompetence' and 'acquiescence' (and resistance to this – Ropley, 2004) and the ways in which service-user identities are

connected to staff identities in case worker consultations (Wareing and Newell, 2005) among other topics.

Conversation Analysis permits us to inspect the very fine details of interaction, and thus provides us direct empirical grounds for our claims. This is important when the issue being studied is irredeemably local and interactional, as of course is 'refusing' or 'resisting' (or its counterparts 'inviting', 'insisting' and so on). Our use of CA is bolstered by essential support from our ethnographic research on site. This is crucial here, as the communication difficulties of the residents are so marked that special background is crucial to interpret what particular behaviours and vocalisations might mean to the residents and staff. Thus, for example, one needs to know that a resident's apparently meaningful silence in response to a previous turn is accountable by their general inability to produce speech; or that a certain resident uses a certain vocalisation generally to signal distress or pain; and so on.

Analysis

One activity: being weighed

We have chosen two episodes within a single morning's activity (the residents' monthly weigh-in), so as to reduce the ethnographic background information necessary for the reader to understand the framework of what is going on. However, even though we focus on this one activity, what we shall see is in keeping with the routine proposals and acceptance of/resistance to other activities in this service.

Ethnographic background

Recording residents' weight serves a monitoring function as an index of the residents' health. It takes place monthly. During the daytime in this house, residents are usually occupied (or indeed sit or wander unoccupied) in the lounge or in other rooms. Weighing normally involves asking the residents firstly to come through to the dining room, or leading them into it, and then getting them to approach and step up onto a set of ordinary bathroom scales about two inches high. That is what happens on this occasion.

While some of the residents come immediately for weighing, the recording shows that others appear reluctant and are encouraged repeatedly. A couple of residents appear to be apprehensive about stepping up onto the scales, and only do so while holding onto the staff or the wall, suggesting that, for some at least, there may

be a problem of balance or a fear of falling. The episodes we examine here concern the three staff on duty (one of whom is off-camera, in another room) and two residents, Matthew and Steven, who each (in separate episodes) display obvious resistance to getting on the scales. We shall describe Matthew's case first.

Case 1. Matthew's refusal to be weighed, and how staff deal with it.

We join at the point where staff member Sandy ushers in residents Matthew and Mona. They enter a room in which are visible two residents not apparently engaged in any specific activity; the researcher Chris, standing out of the way, camera in hand; and staff member Jill, who comes forward to receive them. Mona is slightly behind Matthew, who thus becomes first to be asked to take part in the activity.

At this point it is useful to record that Matthew is a 36 year-old man of small stature (a little over 4 feet tall). Matthew has a vocabulary supposed to number some 20 words, though few of these are evident on a day-to-day basis. He also makes use of expressive sounds and gestures, particularly in situations that he finds dissatisfying or distressing.

Before the first extract we should explain what the reader will see. In an effort to capture as much of the details of the speakers' delivery, and the timing, of their speech and actions, we have used conventional CA notation. The full glossary is in an Appendix to this article, but it is worth explaining two features which, unfortunately, impede easy reading, yet are crucial for understanding what is happening. One is the use of descriptions in italics (e.g. *back to camera, leans down to face Matthew*) in an attempt to capture relevant parts of the visible scene. The other is the use of square brackets ([]) on adjacent lines to show that the material enclosed is done at the same time. So, for example, in Extract 1, in the one second between Jill's two turns at speech (lines 5 and 8), we see Sandy take Mona past Matthew towards the weighing scales.

Extract 1: VA5 min 1.59. Matthew's first refusal

01	Jill	((<i>back to camera, leans down to face Matthew, holds</i>
02	→1	<i>out hand towards him</i>)) >↑dy'wanna get weighed?<
03		(.3)
04	Matt	((<i>while turning away from Jill to face the table</i>)) °nehr°
05	Jill	no:?
06		[(1.0)]

07 [((Sandy takes Mona past Matthew towards scales))]
 08 Jill go on then, (.2) Mona can go:,

Refusal acknowledged and the matter dropped.

Staff member Jill offers Matthew what will be the first of many invitations to be weighed (marked "1" in line 2). How does he react? Ethnographic observation provides background evidence that Matthew's soft utterance at line 4, which we transcribe as "°nəhr°" is a sound that he uses elsewhere to signify a range of negatives - disagreement, distaste or, as we may understand it here, dissent.

By itself this background information is only suggestive, and as CA theorists observe, potentially misleading (see, for example, Schegloff, 1997, on the use of alleged background context). What is decisive is two immediate sources: Matthew's own turning away from Jill, which is a generally-shared convention requiring no special interpretation; and - most manifestly - Jill and Sandy's immediate understanding that Matthew means 'no'. Jill explicitly does a check-confirming "no?" (see Houtkoop-Steenstra, 2000 especially ch. 6 on how questioners deal with answers), and Sandy endorses this understanding by beginning to lead the other resident past Matthew to take her turn. Jill concurs.

The immediate availability of the next resident allows the staff members to drop the issue of Matthew's compliance. A period follows in which Mona is successfully weighed, without incident. Then another resident, Julie, appears and is brought to the scales and weighed, though with somewhat more trouble (which we shall not describe here). Jill then turns to Matthew again.

Extract 2: VA5 min 3.05. Matthew's second refusal

01 (?) [((noises & laughter celebrating Julie's weighing))]
 02 →2 Jill [((off camera, presumably to Matthew)) >d'y wanna<
 03 another go,
 04 (.3)
 05 Chris w'done Jul [i.e.
 06 →3 Jill [d'y wan' another go,
 07 (.5)
 08 (?) ((laughter))
 09 (.3)
 10 (?) ()
 11 [((camera now swings round to find Jill bending
 12 [down and holding Matthew's hand))
 13 →4 Jill c'mon (.3) >sh'we get weighed?<

- 14 Matt [(°nerh°)=
 15 [((Matthew turns away to table))]
 16 Jill =weighed? (.) [no (.) we had a clear no: there,
 17 [((Jill drops M's hand, straightens,
 18 looks up & away from Matthew but to no one in
 19 particular, then to Chris, then back to Matthew
 20 again))
 21 Chris Right.

No-blame reissue of invitation

Recall that in its first incarnation, (in Extract 1 above) the staff's request to Matthew was a simple invitation: "dy'wanna get weighed?", which was refused. Notice how Jill re-issues the request (marked "2" in line 2). She asks: 'd'y wanna another go'. This on the face of it is odd, as he has not 'had a go' yet, in the sense of making any attempt to approach, still less stand on, the scales. This is a *no-blame repair* (repair, as a feature of conversation, has been studied since Sacks, Schegloff and Jefferson's seminal 1974 article on turn-taking in conversation) of Jill's initial question, which elides responsibility for the problem it caused. Indeed, it implies that there was no problem, and that the request had been already partially successful, as if Matthew had in fact made a stab at mounting the scales. It is met with silence. Jill reissues it ("3", line 6), as if it had not been heard or understood; but no-blame formulation or not, this third invitation also fails.

Jill is then more direct, asking: 'Shall we get weighed?' (invitation 4, line 13). The collective phrasing ('we') implies the task is one they are both doing together, rather than being an individual matter of choice for Matthew. This is another no-blame repair, as it issues the invitation *as if for the first time*. It implies that the two previous attempts have been simply misunderstood, or not heard, or been otherwise inoperative; no blame attaches to Matthew (or to Jill) for their failures. This is a regular feature of self-initiated repairs (which are the preferred form; see Schegloff, 1992). However, Matthew still refuses (line 14). He repeats the "neh" sound we noted in Extract 1 above, and turns away from Jill to face the table. Better evidence that what he says and does is taken as a refusal is made manifest by his interlocutors: Jill expressly announces (to the room at large, but possibly for the researcher Chris's benefit) "we had a clear 'no' there". Three no-blame reissues of the invitation to get weighed have failed.

A dilemma for staff

What, now, are the members of staff to do? On the one hand, they could accept Matthew's four refusals. That would be in the spirit of the overarching institutional policy of encouraging and respecting choice, enshrined in this residential home's written "philosophy of care" and at each level of authority above it, from the policies of the regional Trust to those of the national Department of Health. This seems to be the line that Jill takes, as the extract below - which follows on immediately from the one above - shows.

Extract 3: VA5 min 3.10. Jill apparently respects Matthew's refusal

22		(.3)	
23	Jill	[you don't have to.]
24		[((walks away from Matthew, towards scales))]
25		(1.0)	

Jill announces that Matthew need not be weighed, and seemingly walks away. His choice of refusing an activity seems to be respected.

However, while respectful of individual rights, the service staff are also subject to two forces that pull the other way. One is that they may consider it to be in the residents' best interests to get weighed, so that any health-related fluctuations will be spotted. This, of course, generalises to any activity which the institution believes is subject to health and safety issues; our ethnography reveals it in such activities as toileting, food-preparation, and so on. The other consideration that the staff may have in mind is that they personally, as employees, will be held accountable for a missing entry in the records. If either of these forces hold sway, the staff may feel entitled to mobilize a commonplace practice, often seen in this (and other) residences: to treat Matthew's 'refusal' as a merely temporary reluctance that will melt under persuasion and good-natured cajoling. It is this latter practice that wins out in this case. See how, in extract 4 below (which carries on immediately from extract 3), Jill breathes new life into Matthew's weighing.

Extract 4: VA5 min 3.12. Jill revives the invitation with a minimised task

26	Jill	((off camera)) what I <u>will</u> do is=	
27	Chris	=e's gorris <u>eye</u> on it (.) °though°=	
28	Jill	[= try seeing (1.2) if (2.4)]
29	Sandy	[((approaches him and holds her hand out))]

30 →5 [you wannu go there (°n °)]
 31 [((Jill brings scales over to Matthew and places
 32 [them at his feet))]
 33 [((Matthew slowly turns 90° away from Jill))]
 34 Jill ↑d'you want to step on 'em?

Minimised task

Despite herself explicitly announcing that Matthew need not be weighed, Jill suggests there is some room for interpretation. Her 'What I will do" (line 26) proposes another course of action to pursue her request, implying - again in a formulation that does not blame Matthew - that the fault may have been in the difficulty of what was originally wanted. Chris the researcher seems to endorse the possibility that Matthew's no was not definitive by saying 'He's got his eye on it (i.e. the set of scales), though.'

Jill goes to get the scales, implying that it was the distance (a few feet) that was the problem. Sandy takes her cue from Jill's actions by explicitly approaching Matthew with her hand outstretched (as if to help him onto the scales) and issuing a direct invitation (marked "5", line 30). Jill arrives with the scales and places them at Matthew's feet. She then issues the sixth invitation: "d'you want to step on them?" (line 34). Extract 5 follows immediately.

Extract 5: VA5 min 3.19. Matthew's sixth refusal

35 →6 Matt °nehr° ((Matthew edges his feet away from the scales))
 36 Jill no:?:
 37 [((Jill picks up scales))
 38 Sandy [((makes sweeping gesture and giggles))
 39 Sandy (you need to take the [oh he said)
 40 [((Jill carries scales back, facing camera, smiling))]
 41 Jill [↓°no:°]
 42 Jill that was a no:.
 43 Chris yeah.
 44 Sandy ((walks past Matthew, touching him on shoulder as
 45 she passes & leaves the room))
 46 (.5)
 47 Jill okay:h ((deposits scales in original position and
 48 walks back towards Matthew))
 49 Chris so who's left.
 50 Jill [((turns head over her shoulder back towards Chris))]
 51 [that was a no.]
 52 ((Jill walks past Matthew, ruffles his hair as she passes
 53 and follows Sandy out of the room))

54 Sandy ((*from outside the room , apparently in reponse to*
55 *Chris' question*)) Perry and ().

At the start of extract 5, Jill has placed the scales at Matthew's feet. Matthew repeats the *nehr* sound and shuffles his feet away from the scales. Jill echoes this as a conventional *no* refusal, and removes the scales (lines 40-2). In line 47 she says 'Ok' which is commonly used to as a pivot between topics (Beach 1995) and reiterates her understanding that Matthew's behaviour constituted a refusal (line 51). Chris, the researcher, goes along with this proposed termination of the issue, making operative the new, but institutionally relevant (and business-as-usual) topic of next-to-be-weighed.

Summary of staff's treatment of Matthew's refusals so far.

At this point we can see that Matthew has given multiple signs that he does not want to take part in the activity. Apart from his non-standard vocalisation, he has turned his body away from the direction of the scales, looked away, not taken a hand offered to him, and not stepped onto (indeed, edged away from) the scales when they were brought to him. We have also seen that although these behaviours are recognized (indeed explicitly announced) to be refusals, the staff persist in their requests, indicating that Matthew's refusals are not treated as definitive.

However, neither Jill nor Sandy are ordering Matthew to get on the scales, or invoking their authority as staff members. They are solving their dilemma (between respect and persistence) by no-blame encouragement – their responses treat Matthew's refusal as either due to lack of support or encouragement on their part, or due to problems in the way they have issued the invitation.

Jill's "okay", and the move to next-resident-in-the-queue, suggests that Matthew's part in the episode is over. However, although Sandy and Jill have now moved out of the room, we hear Rose, who has been in the kitchen, make an intervention. Extract six follows some 20 seconds on from extract five (the line numbers give an indication of how much material we have skipped).

Extract 6: VA5 min 3.31. Rose's intervention and Matthew's seventh refusal.

(Rose is off- screen throughout; she is looking through from the adjoining kitchen)

67 [((*Matthew advances to a glass-fronted cabinet and*)
68 [*makes to open its door.*)]
69 Rose Matthew.

70 [(1.5)]
 71 [((*Matthew immediately withdraws hand, head*)]
 72 [orientation moves midway between cabinet and the]
 73 [direction of Rose's voice)).]
 74 Chris °C'mon°,
 75 →7 Rose (g)won stand on thee- scale.
 76 ((*Matthew glances at Rose, then looks at floor, slowly*
 77 *turning body back away from cabinet, towards table;*
 78 *he brings his hands together across his chest*))
 79 Matt neeah:.

A change in register: escalation

A simple narrative will help convey what is happening in (and just before) Extract 6. Matthew makes his way to a cabinet which houses videotapes, which the ethnographic record shows are among Matthew's favourite objects. In other words, he looks to initiate a quite different activity, under his own steam. Matthew is about to touch the cabinet when Rose calls his name. He freezes. In contrast to Jill and Sandy, Rose opens with an utterance from a different register. At line 75 (marked 7) Rose issues the direct order: “(g)won stand on thee- scale”. In response, Matthews turns away from the scales and says “Neaah”. Rose counters this with a disaffiliative, challenging “yes” (line 80 below, marked 8). Clearly, Rose is dealing with Matthew's refusal very differently. She is upgrading Jill and Sandy's no-blame invitations - insistent as they were - to an unambiguous instruction. Matthew covers his face and repeats “neeah” (line 81).

Extract 7: VA5 min 3.56. Rose insists; more refusals (follows immediately on from above)

80→8 Rose yes:.
 81 Matt neeah. ((*head down, raises right hand to cover side of*
 82 *head nearest Rose*))
 83→9 Rose YES,
 84 Matt nu- euh. ((*drops hand, brings hands back in front of*
 85 *chest*))
 86 ((*some talk is hearable from the next room, but it seems*
 87 *unrelated to this exchange and we do not transcribe it*
 88 *here*))
 89→10 Rose ↑go on, (.)↑stand on the [sca:les
 90 Matt ((*jerks hand down*)) [nee:aurh ((*begins to move*
 91 *back to table, away from scales*))
 92→11 Rose I say yes.
 93 ((*Matthew turns and walks towards exit door, hands*
 94 *clasped*))

95→12 Rose Come on. (.) MATTHew.
 96 ((*Matthew stops, turns away from Rose, towards wall*))
 97→13 Rose THIS way,
 98 ((*Matthew stands right up against, and facing, the wall,*
 99 *hands clasped*))

There is no mistaking Rose's position on the matter: Matthew's refusal is unacceptable. Her attempts to get Matthew to comply are more brusque than Sandy or Jill – she raises her voice in line 83, directly counters Matthew's vocalisations with her own 'Yes', and then re-issues the order 'Go on, stand on the scales' (marked 9 & 10). When Matthew still says 'nee:aurh' and moves away from the scales (lines 90 & 91), she explicitly acknowledges her own will to be different from his own: 'I say yes' (marked 11, line 92). Each of these steps is characteristic of the escalation of argument (see Antaki, 1994, Dersley & Wootton, 2001). The result of this approach is what we might see as a more extreme display of refusal by Matthew – he withdraws, to go and stand facing the wall (lines 98 & 99).

The conflict is unresolved, but fades as Jill and Sandy return with another resident. We hear no more from Rose. A little over a minute passes as they weigh this other resident, then seat him in a chair nearby. We rejoin the scene as Sandy approaches Matthew, who has been standing square-on to the wall the whole time, though with head turned to follow the action.

Bodily persuasion as a last resort

For reasons of space we do not transcribe this stretch of action (a transcript is, however, available from the authors). Briefly, Matthew is facing the wall throughout. Sandy brings the scale next to his feet, puts her arms around him. As she gently tries to manoeuvre him onto the scales, Matthew makes distressed-sounding vocalisations. Sandy repeatedly says 'come on' in a sing-song voice, the intonation of which seems designed to respond to Matthew's – while he is making crying noises after her invitations, she uses a lilting, soothing intonation pattern (see Rapley, 2004 for a discussion on workers using sing song intonations to people with intellectual disabilities).

This description shows two contradictory things: Sandy's gentle encircling of Matthew with her arms, and her soothing pitch might be heard as indicating her support for Matthew and a visible indication that she has heard his distress; on the

other hand, her persistence in the face of this points to a refusal to accept his response. Again, at the end of the extract, Matthew adopts a more extreme response – he pulls away from her and faces the wall, leaning his forehead against it. This position is uncompromising.

Coda: a positive gloss

At this point, the staff bring in and weigh another resident, so their business with Matthew seems finally to be over. But it is not, quite. There is a revealing coda which brings out an important resource the staff have of explaining away problems by appeal to a quirk of Matthew's personality. We pick up the story about half a minute after the end of the last extract. The staff's focus has been on another resident. We join just after Sandy has loudly, but indecipherably, addressed her colleague in the next room, then starts to move off.

Extract 8: VA5 min 6.48. Sandy finds another activity for Matthew

01 Sandy () ((said loudly, but not clearly.
 02 Possibly designed for a listener in another room; there
 03 is a faint reply, possibly from Jill, off-screen))
 04 Sandy ((about to move past Matthew)) ()
 05 Sandy ((stands in front of Matthew and looks at him)) hmm?
 06 (.5)
 07 Sandy come on let's go. ((holds hand out to him))
 08 [(2.0)]
 09 Matt [((hands clasped, does not take hers))]
 10 Sandy come on,
 11 Matt °nurh°
 12 Sandy >you're not coming,< ((drops hand))
 13 Matt nuh. ((edges away))
 14 Sandy alright then, (.) see you later.
 15 ((Sandy walks towards doorway and stops there))
 16 Sandy y'com:in?
 17 (.)
 18 Sandy ↑come on
 19 (4.0)
 20 Sandy come on Matthew.
 21 (2.0)
 22 Chris ((moves towards matthew)) we goin'?
 23 [(5.0)]
 24 [((Matthew stands without moving as Chris brings]
 25 camera to within touching distance))]
 26 Matt ((starts [to move towards door])
 27 Sandy [look at you:., (1.0) you have to- (.2) wait for

28→14 your own [time °to come° ((*Sandy goes off screen*))
 29 Chris [yep,
 30 ((*Matthew leaves dining room*))

Here Sandy is no longer inviting Matthew to be weighed. In a signal that that business is now over, she is inviting him to leave the dining room with her. In this extract we see that Sandy's initial invitation 'come on let's go' (line 7) is not responded to. She then goes to stand in doorway and we can see she treats Matthew's non-response as a 'no' by saying 'you're not coming' and 'all right, see you later'. However, just as we have seen in previous extracts, this does not lead to the invitation being dropped, and she repeats 'come on' twice after this. Chris picks this up, and in line 26 Matthew begins to respond. So far, that merely repeats the pattern we have already established. What is especially revealing about the extract is what Sandy now says in lines 27-8, as an explanation of Matthew's tardiness in accepting her invitation to leave the room: 'you have to wait for your own time to come' (marked 14, lines 27 & 28).

We would suggest that what Sandy is mobilising is a rhetorical trope which puts a positive gloss on Matthew's behaviour - and on the staff's reaction to it. It claims that Matthew's 'refusals' are (merely) signs of his well-known, universal and long-standing disposition to want to do things at his own pace. Sandy makes this as a comment on his reluctance to leave the room, but it comes hard on the heels of the protracted, and unconsummated, business of his failure to be weighed, and might therefore be applicable to both. In both cases, what will have looked like "refusing" might therefore be treated as a matter of him just wanting to "wait for his own time" to agree. This formulation, is, as Holt and Drew (1998) notice about such idioms, designed to bring a trouble to a conclusion by setting it down to an immutable and unchallengeable description of the way the world is.

Case 2. Steven's refusal to be weighed, and how staff deal with it.

Matthew's many refusals were dealt with in a variety of ways by staff; we now move on to the case of another resident, Steven, to pick up similarities and differences. Steven is registered blind and has his eyes shut most of the time. Because of his lack of vision Steven requires physical assistance to move around the house. He is more verbally capable than Matthew; his vocabulary is greater and he is able to construct phrases several words in length. However, like Matthew his communicative

abilities are not readily apparent on a day-to-day basis and typically they only become apparent when he is prompted and supported to use them.

At the start of extract 9 below, Sandy and Matthew are in the kitchen when Jill and Steven appear in the doorway, arms linked. Sandy is behind them.

Extract 9: VA5 min. 6.19. Steven stops (refuses?) in dining room doorway

- 01 Jill say hello Chri::s
 02 Sandy Oh [::
 03 Chris [Oh and Steven as well (.) ↑hi Steven
 04 Steven ((halts in doorway))
 05 Jill ((also stops, looking back at him))
 06 Jill whereyu going? (.) >d'yu wantu< come in
 07→1 and have a nice drink, (.) 'n get weighed
 08 Steven ((shuffles feet in doorway but not going in,
 09 arms linked with Jill))
 10 [(1.7)]
 11→2 Jill [drink and weighed?]
 12 [(1.5)]
 13 Steven [((head sways side to side, brings hand to mouth,]
 14 [turns head against door)]
 15→3 Jill d'yu wantu come in? (1.6) Steven?
 16 Steven ((lifts and turns head so facing into room, takes
 17 hand from mouth))
 18 [(2.8)]
 19 Jill [((moves arm down from linked arm with Steven]
 20 [and takes his hand. Leads him a [into room))]
 21 Jill [↑come on
 22 Steve ((stops, drops head, brings palm of hand to open
 23 mouth as if biting))
 24 Jill no [::↑
 25 Steven [((pulls hand away, turns away from her and
 26 steps back into doorway, facing door, hands clasped
 27 together))
 28 [(1.6)]
 29 [((Jill shakes head and turns back into doorway))]
 30→4 Jill no, (.) we've go' a clear no here ((steps back into
 31 doorway))
 32 ((Jill takes Steven's hand, facing into corridor))
 33 Jill where d'yu want to go
 34 Steven ((shakes head)) (°fro oom°)
 35 Jill [((drops head nearer his mouth))
 36 Jill [where?
 37 Steven (°th' fro oom°)
 38 Jill front room? ((Jill and Steven, hand-in-hand, begin
 39 to walk down corridor)) (1.2)
 40 Jill front room? ((they disappear from shot))

Repair to a more minimal request

We see in the extract above, as we did with Matthew, how the staff come to reissue the invitation in a more minimal form. When Steven halts in the doorway (line 4), this might be a refusal. Jill treats it as (merely) a change of direction by asking where he wants to go, then repeats her invitation. Possibly recognizing potential trouble, she prefaces the weighing invitation with offering him a drink ('drink and weighed' – lines 7 and 11, marked 1 and 2), as if the two activities are coupled. However, Steven then turns and faces the doorframe (line 15). Rather than recognizing this as his refusal, she re-issues the invitation, this time editing out the activity (weighing) and offering a general invitation to enter the room: 'd'yu wantu come in?' (line 15). Faced with no clear acceptance of this invitation (there follows a silence for 2.5 seconds; this is very indicative of a dispreferred, in conventional metrics of pausing - see Jefferson, 1988), Jill then issues a call for his attention (his name with a questioning intonation – marked 3, line 15). As we saw with Matthew, this way of dealing with refusals is a no-blame repair; it formulates his non-response as due to a lack of attention to her question rather than his declining the invitation

At line 16, Steven turns and once more faces into the kitchen. Jill treats his shift in body orientation as an opportunity to proceed further. She advances a few steps, holding Steven's hand and leading him into the room, saying 'come on' (line 21). This change in Steven's bodily position can be seen, then, as potentially interpretable as a change in his attitude towards entering the room. Like the sequence in extract 9, it is precisely these types of events which provide licence for staff persistence, since they indicate that refusals might not always be definitive.

However, Steven then stops and brings his open palm to his mouth (as if he were biting himself – line 22). Jill's 'no' at this point might be a request for him not to bite his hand, or she might be voicing her interpretation of his behaviour (i.e. he does not want to go into the kitchen). Steven then pulls his hand from hers, turns away from Jill and the kitchen, and steps back to the doorway. At line 30 (marked 4) Jill clearly treats Steven as refusing ('we've got a clear no here'; c.f. the same announcement about Matthew, Extract 2, line 16)), and she stops trying to get him weighed by asking him where he wants to go. Steven provides a verbal response which we were unable to hear clearly on the recording, but which Jill's takes to be 'front room' (a term used in the UK to refer to the 'lounge' or 'sitting room'). They then leave the kitchen, and we can see that Steven's choice has been respected.

However, as with Matthew's case, what seems to be a respectful conclusion is only a temporary hiatus. We pick up the action with extract 11. Here we see Sandy trying to weigh David. The scene begins about one minute after Steven has left the kitchen at the end of extract 10. Sandy comes out of lounge with Steven, holding his hand and walking with him towards the kitchen. Matthew passes them. Jill is standing in the corridor.

Extract 11: VA5 min 7.50. Steven is led back to the kitchen.

01 Sandy d'you wanna be weighed darling (.) mh?
 02 [(1.7)]
 03 [((Sandy leads Steven down corridor towards kitchen))]
 04 →5 Jill that's as far's I gottim
 05 Sandy [(1.4)]
 06 [((Sandy leads Steven down corridor towards kitchen))]
 07 Jill Matthew's runnin away
 08 Sandy mkay
 09 [(4.0)]
 10 [((Sandy still leading Steven along, Jill follows))]
 11 ((Steven stops [on threshold of kitchen and backs away))
 12 [((Sandy stops, turns back))
 13 Sandy [()] [(giggles)
 14 Jill [see what I mean
 15 Steve [((backs out of doorway into corridor))
 16 Sandy ((holding Steven's hand, points at floor by Steven's
 17 feet)) put the weigh .hhh put the scale there (.4) then,
 18 Jill [ss get you (down)
 19 [((Jill walks past Sandy into kitchen))
 20 Sandy [we'll put the scale here
 21 2.0
 22 Sandy why don't you wanna be weighed

Reformulation of 'refusal'

In the first instance it was Jill who was taking the lead in trying to persuade Steven to get on the scales. A minute later, Sandy has a go, and it may be that she is more successful. We pick up the scene as she is leading him down the corridor back to the dining-room: 'd'you wanna be weighed darling' (line 1). That staff effectiveness is an issue is evidenced by Jill's comment, as they walk down the corridor, 'that's as far as I got him' (marked 5, line 4). This way of construing the situation is one which places staff success or failure at getting the task done as central, rather than their success at recognizing Steven's expression of preference.

Again we see Steven doing things that staff interpret as expressing his desire not to be weighed. He pulls back in the doorway and edges back into the corridor. Sandy then suggests bringing the scales from the kitchen and putting them at his feet. Just as with Matthew (extract 4), this attempt to solve the problem treats his behaviour as (possibly) a refusal to go into the kitchen, or to walk the extra steps to the scales, rather than to get weighed per se. However, her next question ‘why don't you wanna be weighed’ (line 22) treats his behaviour as a refusal to get on the scales. Note that this is not a question that Steven would normally be able to answer given his communicative difficulties, but rather is one which fills the gap when Jill is getting the scales, and one which credits Steven with reasons for his refusal. In a further development (not shown), Jill persists (‘mm? ... come on’) and Steven makes a muffled shrieking noise, moving further away again. In response to this, Sandy drops her enquiries about being weighed and suggests a different activity – singing. This might be glossed as a distraction sequence, since it occurs while Jill is fetching the scales and they are about to try to weigh him again (extract 12).

Extract 12: VA5 min 8.17. Steven is almost manoeuvred onto the scales

35 Jill don't think [he will t'be honest
 36 [(*Jill returns holding scales*)] he feels un (.9)
 37 [(*puts scales down in doorway by Steven's feet*)]
 38 Jill [safe
 39→6 Steven [EUUoo:.hh ((*shriek with open palm covering mouth*))
 40 ((*drops hands to chest-height when vocalisation stops*))
 41 Jill [Steven?
 42 Sandy [t's allright,
 43→7 [(*Sandy hands on Steven's waist, she moves his body round*
 44 *so he is facing kitchen and scales*))
 45 Steven eeyooo::
 46→7 Jill >Come on sweetheart< ((*takes Steven's wrist*))
 47 Jill [can you step on here?
 48 Steven [°eeyoo°
 49 Jill step [up
 50 Steven [°oo° ((*edging towards scale, hands clasped together,*
 51 *Sandy's arms around his back, Jill holding his hand*))
 52 Sandy step up
 53 ((*Steven puts right foot on scales*))
 54→8 Jill [well do::ne
 55→8 Sandy [good ma::n
 56 ((*Steven raises left foot into air*))
 57 Jill now [step up
 58 Sandy [step up

darling?), but which sounds on the tape like ‘I don’t’. Steven might be indicating here that he does not want to stand up - this interpretation is supported by the fact that he makes no move to get up when encouraged, and begins to sing while rocking back and forth. Both Jill and Sandy take up his change of activity, laughing, clapping and joining in. After the singing is over, they help him up and back to the lounge without trying to get him back on the scales again. His successful refusal, and creative change of activity, is accepted by both Jill and Sandy. Their praise at the end displays, to all parties, that Steven’s exercise of choice has been accepted with good humour and without damaging their relations with him.

Discussion

Refusing staff requests is a test of the staff and the system, as it puts in conflict two opposing institutional objectives: to respect choice and to get the job done. We set out in this article to use video records to examine, for the first time, what happened on two occasions when residents with severe communication difficulties tried to refuse an activity proposed to them by staff.

We have, we think, achieved two things. The first is that we have put flesh on the observation that it can be hard to for people who have little symbolic language to exercise choice in routine aspects of their lives. The second is to have revealed the detailed work-practices by which staff members - usually sympathetically and unaggressively, but not always - override residents' refusals. In our examples, although the staff repeatedly recognized that residents preferred not to be weighed, and that it was not necessary, nevertheless they persisted in encouraging them. These scenes starkly show the conflict between two service agendas – that of encouraging self-determination and empowerment through offering support in ‘person-centred’ ways, and that of providing ‘care’ through a set of routine institutional procedures (for discussions of this conflict see Bannerman et al, 1990; Dowson, 1997; Harris, 2003; Jenkinson, 1993; Jenkinson et al, 1992; Kishi et al, 1988; Stancliffe, Abery & Smith, 2000). We see here that although the former is recognized and acknowledged by the staff, the latter seems often to dictate their responses. Indeed it takes some persistence and creativity on the part of residents Steven and Matthew before they find their wishes finally respected (and we must acknowledge that eventually the staff do respect their choices). Neither was successfully weighed on the morning in question.

While in some contexts it might be argued that the staff members are persisting to ensure the safety or health of the resident, we believe this is not the case in the examples presented here. There is no life-or-death issue at stake in insisting that every resident participates in the weighing session, and this is acknowledged by the staff. Rather, we believe the activities being insisted upon are being pursued for the sake of getting all residents 'done' at the same time, in pursuit of a tidy schedule of work activities, and because these interactions are locations for the demonstration and instantiation of staff effectiveness and authority. The institutional imperative trumps the residents' exercise of choice.

The extracts illustrate a range of resources on the part of residents that staff recognize as refusals: edging one's feet away from an activity, stopping in the doorway of the room in which the activity will occur, turning one's head away, standing facing the wall, standing still when encouraged to approach a piece of equipment, the use of 'proto-words' such as Mathew's 'nehr'/'neeyah', and vocalisations such as shrieks. In response to these, staff have a range of resources with which they attempt to counter these refusals: appreciating resident's behaviour as something other than refusal; formulating the invitation again in a no-blame format; minimising the task required; escalating the invitation to a request and an order (with gentle 'sing-song' intonation, or more brusquely); moving the person bodily; and positively glossing the proceedings. We should note the gentle way in which the staff almost always acted, and that when they did accept the refusal, they did so in a 'no-blame' way – for example, stroking Matthew's back and shoulder (indicating their relationship was still intact) and celebrating and joining in the Steven's creative response of treating the scales as a horse and singing an appropriate song. The drive to maintain intersubjectivity (Garfinkel, 1967) - an agreed, positive, display of understanding what is going on - is as strong in this residential home as it is anywhere in social life.

It is important to set these extracts in the context of other sorts of invitations that occur in the house. Our ethnographic work, over some nine months, revealed similar behaviour in a range of situations in which residents are being invited to do things (e.g. go to the toilet, go to the dining room for a meal). On some occasions, the resident simply does not respond – that is they make no vocalisation or movement that is easily interpretable as an acceptance or refusal, although a non-response might be taken to indicate a refusal. However, in these situations the staff usually persist in

their encouragement, and eventually the resident might comply. We saw this where Mathew is invited to leave the kitchen by Sandy. Since this means that non-responses can sometimes be ambiguous, or that residents can change their minds after some encouragement, this gives a certain licence for staff to persist when initial invitations do not appear to be accepted. In the extracts above, however, what we see are staff acknowledging that the person has said no, yet still persisting.

In conclusion: we have examined in detail two episodes in which people with severe communication difficulties attempt to refuse care activities suggested by staff. Empirical studies which seek to understand and promote self-determination have tended to focus on broad indices of choice in such things as food, leisure activities and living arrangements (eg Hatton et al, 2004; Stancliffe 1995, 1997; Stancliffe & Abery, 1997; Stancliffe et al, 2000), or on developing techniques to teach people choice-making skills (eg Browder, Cooper & Lim, 1998; Cooper & Browder, 1998; Nozaki & Mochizuki, 1995). This paper documents what we can learn about the abstractions of empowerment and disempowerment as they cash out in lived experience.

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Transcription Symbols

(.)	Just noticeable pause
(.3), (2.6)	Examples of timed pauses
word [word	
[word	The start of overlapping talk.
.hh, hh	In-breath (note the preceding full stop) and out-breath respectively.
wo(h)rd	(h) shows that the word has "laughter" bubbling within it
wor-	A dash shows a sharp cut-off
wo:rd	Colons show that the speaker has stretched the preceding sound.
(words)	A guess at what might have been said if unclear
()	Very unclear talk.
word=	
=word	No discernible pause between two sounds or turns at talk
w <u>o</u> rd, W <u>O</u> RD	Underlined sounds are louder, capitals louder still
°word°	Material between "degree signs" is quiet
>word word<	Faster speech
<word word>	Slower speech
→	Analyst's signal of a significant line
((<i>sobbing</i>))	Attempt at representing something hard, or impossible, to write phonetically