



Wheelchair Service Review

Qualitative report

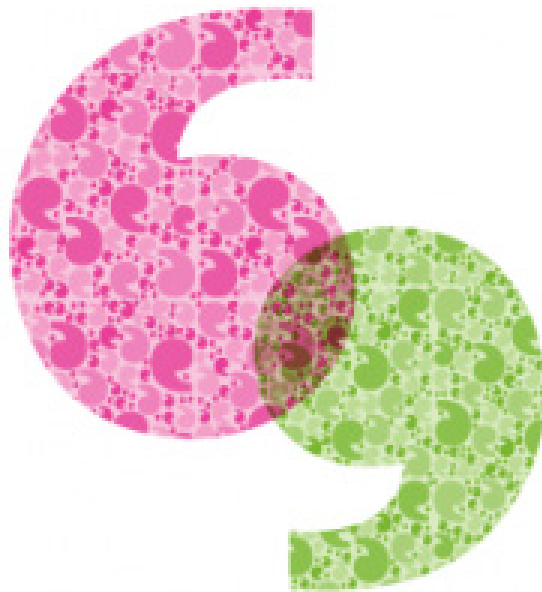
Two focus groups and 24 in-depth interviews with service users regarding the services delivered by Millbrook Healthcare

**Facilitated by Healthwatch Hampshire for West Hampshire Clinical Commissioning Group
January - March 2017**



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About Healthwatch

Healthwatch is the independent consumer champion for health and social care in England. Healthwatch's function is engage with local people to seek views about locally delivered services, to signpost service users to relevant information and to influence the design of local health and social care provision. Healthwatch Hampshire is part of a network of local Healthwatches across 148 local authorities that launched in April 2013. Healthwatch Hampshire aims to understand the needs, experiences and concerns of people who use health and social care and speak out on their behalf. Healthwatch has statutory powers set out in the Health and Social Care Act 2012.



For more information, please visit www.healthwatchhampshire.co.uk or email enquiries@healthwatchhampshire.co.uk

Background

In Autumn 2016 Healthwatch Hampshire was invited by the collective of Clinical Commissioning Groups (CCGs) that commission the Hampshire Wheelchair Service (HWS) provided by Millbrook Healthcare to take part in a service review into the current performance of the service.

The service review evaluated the operation of the process by which people referred into the service, are assessed and receive their wheelchairs, the repair service, all quality aspects of service delivery, demand and capacity, investigation and handling of complaints, and communication processes. The scope of the service and context in which it operates are set out in the full report of

the service review which is available here: www.westhampshireccg.nhs.uk.

Healthwatch was asked to gather the feedback on the experiences and perceptions of service users through focus groups and discovery style interviews (qualitative interviews with service users).

This report details the outcome of the discovery style interviews and the focus groups held to gather feedback from wheelchair service users and professionals (health and social care) who refer people to wheelchair services including the HWS provided by Millbrook.

Healthwatch Hampshire previously published a report 'Wheelchair Services in South Hampshire' in March 2016 in response to negative feedback that received about wheelchair services delivered by Millbrook Healthcare. A public meeting was held at the end of 2015 attended by representatives of Millbrook and West Hampshire Clinical Commissioning Group including the commissioner of wheelchair services.

For more information please go to: www.healthwatchhampshire.co.uk/sites/default/files/wheelchair_report_-_march_2016_final_0.pdf





Aims & Objectives

Based on the feedback Healthwatch Hampshire had already received and the issues that arose at the public meeting organised by Healthwatch Hampshire, it was expected that future concerns would fall broadly into the following categories:

- Perceptions of the service
- Referrals
- Assessments
- Suitability of issued wheelchairs
- Repairs
- Communication
- Administration
- Recommendations from referrers and service users

The aim was to have an open discussion within the discovery style interviews (qualitative interviews with service users) and focus groups with Healthwatch prompting the discussion rather than just seeking a response to a list of questions.

Two focus groups were held. 'Focus group 1' participants represented stakeholders including the MS Society and Disabled Peoples Voice. Several service users also took part. This group was also attended by two professionals representing Hampshire County Council.

'Focus Group 2' was made up of health and social care professionals from Solent NHS Trust who regularly work with service users and refer in to Millbrook services. The group had representation from Occupational Therapists (OTs), administration staff and senior managers.

The focus groups were held on Friday 20th January 2017 between 1pm - 3pm and Monday 23rd

January 2017 between the hours of 10am - 12pm.

The 24 discovery style interviews (qualitative interviews with service users) took place between February 2017 - March 2017.

For more information about the discovery style approach please see:

www2.rcn.org.uk/downloads/professional_development/mental_health_virtual_ward/treatments_and_therapies/chd-discovery-interviewspdf.pdf





Recommendations

Based on findings from both the focus groups and service user interviews, Healthwatch Hampshire have compiled the following recommendations for Millbrook Healthcare and West Hampshire CCG. These recommendations have come from service users, carers, stakeholder organisations and professionals that regularly refer into the Wheelchair service. The recommendations are summarised below and included in full, with service user quotes, on page 29.

Referrals

- Millbrook needs to manage client expectations better. Detail a plan of action with timelines and be upfront about what happens if plans change. Be transparent about what can be accomplished and communicate regularly with service users and referrers to provide updates.
- Millbrook should use an 'NHS.net' email address (or equivalent), which would enable referring agencies to send referrals by e-mail. It would then be possible to confirm receipt of a referral via an automated e-mail and help to improve the audit trail.
- Referral process and assessments could be accelerated and improved if the detailed reports (often provided by therapists) could be attached electronically to the service user's record.
- Millbrook should proactively take steps to inform therapists when they cannot process a referral because it is incomplete or incorrect. (Presently this does not happen and therapists often only learn about problems and delays with their referrals when they contact Millbrook to chase it up.)
- Millbrook should utilise their own CRM systems better to manage the referral process and particularly to track equipment.

Assessments

- It is recommended that there should be provision, by Millbrook, of quick triage for priority cases.

Suitability of issued wheelchairs

- It is imperative that Millbrook address the suitability of wheelchairs issued. It is essential that all wheelchair options are explored and discussed with all concerned so that the most suitable wheelchair for the individual service user can be determined.
- The function, appearance and operation of the equipment needs to be explained to the patient and other relevant persons (if possible) before the equipment and specification is finalised.
- As part of the handover process the client or authorised carer should be advised how to obtain repairs & maintenance for the equipment. This should include details of on ongoing support from the wheelchair service with named contacts and correspondence details provided.

Repairs

- The coordination and management of the repairs operation could be more robust by introducing better service coordination through a dedicated Stores Technician.
- Develop simple systems for planned preventative maintenance such as annual reminder letters and accurate logbooks accessible to users and carers.
- Keep clients informed about their expected wait time and let them know when visits are likely.
- Better integrate the maintenance/repair and delivery side of the wheelchair service with the office staff so that maintenance staff share skills and training across the two areas.



- Millbrook should actively test new and repaired chairs before they are (re)issued as this could help to improve service efficiencies.
- The provision of a dedicated repairs email address. This was seen to help provide both an audit trail and if photos could be attached, it would also provide further evidence of the part that needed to be repaired or replaced. This might help to accelerate repairs as engineers would then be able to visibly ensure that they had the correct part on their vans ahead of a call out.

Communication

- Millbrook need to be more responsive generally (to both service users and professionals) as this would result in a more efficient, dynamic and open culture.
- Millbrook needs to keep customers better informed, more often. Millbrook could let people know in advance how often they will be in contact and during which times and channels it is most convenient to be in touch. Any changes with the scheduling of deliveries, assessments, referrals, repairs, equipment etc. should be noted to the client in a timely manner.
- Millbrook office staff need to have a much better knowledge of their products and services
- Millbrook to give customers a consistent way to provide feedback to ensure they learn about the good and the bad experiences its customers have.
- Millbrook to consider employing more disabled workers in the office as many of them have experience of living with adaptive technologies, and understand from a user perspective, how to answer challenges in the most appropriate and respectful manner.
- Improve liaison between Care Homes, Millbrook and families to enhance care.
- Evaluation - Wheelchair Services should conduct regular audits of clinical outcomes and user satisfaction through active use of feedback forms and other evaluation methods.
- Better promotion of the Millbrook website to service users, carers, stakeholders more widely and referring agencies.
- Provide opportunities for Millbrook staff to meet service users and to understand their situations.
- Provide both disability awareness training and wheelchair familiarisation training to all call centre staff.
- Long waiting times for calls to be answered by Millbrook would be enhanced by 'Place in queue' information when someone is waiting for a call to be answered.
- A list of preferred suppliers would be a useful resource for those who wish to purchase their own chairs.
- Implement a robust engagement strategy by creating improved opportunities for service users to provide regular feedback on the service

Administration

- Utilise the skills and experiences of NHS staff to provide networking, training and shadowing opportunities for Millbrook staff.
- Provide an inventory / checklist when a chair is issued and for each chair to have a unique number which can be linked to a service user.
- Ensure that managers have the right experience and training to accomplish their duties and to take better responsibility for the service as whole.

Feedback and findings: Part One -

Focus Groups

Two focus groups were held. 'Focus group 1' participants represented stakeholders including the MS Society and Disabled Peoples Voice. A number of service users also took part. This group was also attended by two professionals representing Hampshire County Council. 'Focus Group 2' was made up of health and social care professionals from Solent NHS Trust who regularly work with service users and refer in to Millbrook services. The group had representation from Occupational Therapists (OTs), administration staff and senior managers.

The focus groups were held on Friday 20th January 2017 between 1pm - 3pm and Monday 23rd January 2017 between the hours of 10am - 12pm. Feedback from both focus groups is included in the findings below. Quotes have been clearly attributed to the relevant focus group to help provide context.

Perceptions of the service

The management of the wheelchair contract was widely condemned by focus group attendees.

- *There is very poor management of the contract by Millbrook (Focus group 2)*
- *Millbrook is failing to deal effectively with complaints. (Focus group 1)*

Respondents suggest the wheelchair service based in Winchester prior to Millbrook being awarded the contract was superior because it was better funded.

- *Service in Winchester prior to Millbrook being awarded the contract was very good (2013), There is not enough money to provide a good service' (Focus group 1)*

Respondents highlight the out of hours' service, call response times, staff attitude and the availability of wheelchairs from hospital discharge as being improved.

- *Out of hours is better (Focus group 1)*
- *Some staff are very helpful (Focus group 2)*
- *The phone answering response time is now better (Focus group 1)*
- *Allocated a Motor Neurone Disease (MND) OT means and MND patients seem to be prioritised (Focus group 2)*
- *Standard chairs from hospital discharge is faster - They have never met/assessed the patient (Focus group 2)*

Many focus group attendees felt the Millbrook workforce was not fully equipped to deliver the contract in the first instance. New staff brought in to the organisation are perceived to be largely inexperienced, untrained, over worked and ill prepared to deal with the complexities and pressures of the service.

- *The workforce are not equipped to deliver the contract (Focus group 2)*
- *Lots of new staff must have an impact on the overall experience of the workforce and training (Focus group 2)*





- *Staff are being brought in from other areas (Focus group 1)*
- *Staff who work for Millbrook are under extreme pressure (Focus group 1)*

Respondents cite numerous examples where staff, through a lack of adequate training, have subsequently failed to teach service users how to use their equipment properly.

- *'They don't know what they are doing.' (Focus group 1)*
- *There's a lack of staff training, for example, not able to teach service users how to use equipment, for example, how long to charge their battery (Focus group 2)*

Many of the problems associated with the service are perceived to originate from poor governance and an ineffective patient engagement strategy.

- *Poor governance - strategies and policies for example the patient engagement strategy - overly complicated and never implemented (Focus group 1)*
- *No policies, no adherence to the policies they do have (Focus group 1)*

Referrals

Millbrook's eligibility criteria are not widely known amongst respondents which has contributed to some confusion and potential avoidable errors and delays in the referral process. For example, are referrers the right people to decide whether someone needs a manual or powered chair?

- *We have waited over a year for a wheelchair for a person then we found out they didn't meet the criteria. If we had known or known how long it would take we could have provided static seating in the meantime (Focus group 2)*
- *Should the referrer decide whether a service user should have a manual wheelchair or a powered wheelchair? (Focus group 2)*
- *'Like for like' replacements - Millbrook responsibility? (Focus group 1)*

Some claim Millbrook have subsequently made promises to share their eligibility criteria but haven't which has caused further delays and misunderstandings.

- *Solent NHS Trust can only send referrals electronically to a secure e-mail address (...@NHS.net) and as Millbrook don't have this we have to post or fax referrals. We have been told that Millbrook have a secure e-mail address and have asked for it. (Focus group 2)*

When referrals are made to Millbrook, acknowledgment of their receipt is not always forthcoming say respondents. Again, this is seen to contribute to much ambiguity and misunderstanding.





- *You always need to ask for an acknowledgement. (Focus group 2)*
- *You don't get an automatic acknowledgement. (Focus group 1)*
- *You don't get any feedback (Focus group 2)*
- *We never know where service users are in the process. (Focus group 2)*

Millbrook are either accused of not being particularly responsive to referrals, or, they fail to adequately give enough notice to respondents about the assessment process.

- *When Millbrook receive a completed referral, a letter is sent to GP. Millbrook don't chase responses. (Focus group 2)*
- *If a question on the referral form is not answered it slows down the referral process - but therapist don't know if a service user meets the DVLA requirements for Motability (Focus group 1)*
- *There is a box on the referral form - 'do you wish to attend the assessment' but Millbrook don't let us know when the assessments are. (Focus group 2)*

Some respondents claim that OT's are providing detailed reports that either are not being considered or do not seem to be attached to the notes or available at assessment. 'Where are they going?' Ask respondents.

There was also widespread confusion about eligibility Criteria.

- *If it was known earlier that the service user wasn't going to meet the criteria private purchase or the possibility of a static chair could be explored. (Focus group 2)*
- *New referral criteria were published on the 1st September - The timescales are not achievable. This was challenged and we were told that we needed to speak to CCG. (Focus group 2)*
- *What are the criteria for clients in residential care? A wheelchair is often necessary for quality of life - moving around home, going out to the garden, Trips out with family etc. (Focus group 2)*

Assessments

Long waiting times for assessments are a serious concern for many respondents as they can lead to safeguarding issues and have a wider, equally negative impact, on resources elsewhere. There also needs to be more clarity around waiting times, add respondents.

- *Waiting times for assessments have led to serious safeguarding concerns: - bed sores, pressure sores, service user confined to bed, lack of mobility, a student missing two terms of college and loss of independence. (Focus group 2)*
- *Waiting times are having a knock-on impact on wider health and social care services - there's a huge impact on resources that should be used elsewhere also a huge impact on carers and service users (Focus group 2)*
- *We need clarity on waiting times - this needs to be transparent! (Focus group 1)*
- *They say they have cleared the backlog but there is a lack of improvement overall. (Focus group 2)*

Referrers from the focus groups complain that they often do not know when the assessments are taking place and invariably they have to rely on service users to tell them. This can be problematic as some severely disabled service users do not have sufficient cognitive abilities to be able to communicate effectively.



- *OTs do try and attend if they know when the assessment will take place but often they have to rely on the service user to tell them when the assessment is and not all service users have the cognitive abilities to know to let the OT know. (Focus group 2)*

Other people criticise a shortage of documentation within patient notes after assessment

- *No documentations attached to patient notes after assessment - resources? (Focus group 2)*

Respondents also complain of long and often indeterminable waiting times for assessments.

- *19 month wait recently quoted! (Focus group 1)*

These long and often indeterminable waiting times for assessments often do not account for any potential change in a service users condition moreover.

- *Change in service user condition between assessment and delivery of chair particularly if the service user has to wait over a year. (Focus group 1)*

As a result, it seems that some people are being casually encouraged to consider buying their own chair as there is such a long waiting list.

- *Some people are being told to buy their own chair as there is such a long waiting list. (Focus group 1)*

Many respondents complain about the lack of timescales being communicated to people on waiting list for assessments ‘

- *6 months from review to assessment (Focus group 1)*

Others claim the assessment process is seen to be prioritising some people over others which they assumed to be contributing to the ever-growing waiting list

- *Prioritising some people means an ever-building waiting list (Focus group 1)*

Suitability of issued wheelchairs

There was widespread concern over the suitability and safety of equipment issued by the service.

- *Concerns were expressed about the safety of service users (Focus group 2)*
- *The suitability of equipment is an issue: e.g. a manual chair was issued when a powered was needed, a heavy powered chair when there was a specific need for a light-weight powered chair (Focus group 1)*
- *Inappropriate wheelchairs are being issued (Focus group 1)*

Often specialist seating has been prescribed but not subsequently provided which has caused unnecessary discomfort and distress.

- *Poor seating which has cause pressure sores (often specialist seating is required but not provided) (Focus group 2)*

Respondents mention that such is the regularity of inappropriate chairs being issued, the completion of AER's (Adverse event reports) and SIRI's (Serious Incident Reporting) is a regular occurrence as a





result of inappropriate chairs. Referrers complain that this process can be an extremely resource intensive process.

- *AER and SIRI's (Adverse event report) - these are regular as a result of inappropriate chairs being issued - they are resource intensive too! (Focus group 2)*

Focus group participants cite numerous examples where inappropriate chairs have been issued to service users which have led to numerous health and safeguarding issues - some of them extremely serious. In one example, a service user specified specialist seating only to be issued with the wrong seating support; this resulted in the service user being bed ridden in residential care for a year as a result.

- *Examples of wheelchairs not fit for purpose e.g. a very heavy wheelchairs (provided by Ultimate Healthcare see*) provided when a lightweight chair was required due to the carers' needs, moulded seating when specialist seating specified, which lead to safeguarding issues (pressure sores) reclining back recommended - chair with upright back provided which lead to the service user not getting the correct postural support, example of a person bedridden in residential care for a year as a result of unsuitable wheelchair. (Focus group 2)*

Nonetheless, on those occasions when unsuitable chairs are unintentionally issued, respondents complain that, through no fault of their own, they inevitably have to begin the referral process from the very beginning again which is grossly unfair, they say.

- *If the chair supplied is not suitable - back to start of process (Focus group 2)*
- *This (unsuitable chair issued) leads to starting referral process again (Focus group 2)*

Some respondents question whether there is a conflict of interest between Millbrook Industries who run the wheelchair service and its subsidiary Ultimate Healthcare who issue some of the products being widely criticized. There is an extensive belief that the products being supplied by Ultimate Healthcare to Millbrook are inferior and therefore other suppliers need to be sourced.

- *The most expensive chair isn't always the best for the service user. (Focus group 2)*

Referrers mention that the Millbrook service in Southampton appears to be the only equipment service across Hampshire actively requesting and charging for the return of unused equipment. They are annoyed because they feel the returns service should be free of charge to encourage honest use of the service. Service users on the other hand mention that they are unsure of what to do with unused equipment and were not aware of any process to return equipment. Some suggest an amnesty to return unused equipment.

- *They are actively asking for returns in Southampton. Why aren't Millbrook doing this elsewhere? If we raise a collection they charge for it (equipment services) (Focus group 2)*

Respondents would ideally like the repository to be located in a central place where it is more accessible to disabled people - not placed on the edge of the county in Southampton where some people might find it problematic to get to.

- *You can't return equipment to one central place. People sign to say that chairs are owned by the service. (Focus group 2)*

Repairs

Respondents complain about the lack of NHS rehabilitation engineers within the Millbrook service leading to problems caused by faulty equipment and inexperienced, unskilled replacement staff.



- *Have Millbrook got rid of them? Does Millbrook think this role is unnecessary and replaced them with less well paid staff that don't have the same skill set? It puts extra responsibility on OTs. (Focus group 2)*
- *Lots of new staff - lack of experience and need training (Focus group 1)*

Although some improvements in the service have been acknowledged, the responsiveness of the repairs and maintenance service as a whole is still perceived to be inadequate. Some focus group participants have described being put on hold for up to 15 minutes before they could speak to someone over the telephone to report a problem.

- *Still takes a long time to get through on the telephone to report a problem (15 minutes before the phone is answered) but this has improved. (Focus group 1)*

Others describe an often sometimes unhelpful response when eventually they get to speak to someone. These respondents are left with an impression that the onus is on the service user to know their equipment and articulate its problem - not the repairs and maintenance staff.

- *The onus is on the service user to know their equipment*

Some respondents complain that accurate record keeping and monitoring of equipment is too slack; some chairs earmarked for specific users were found to have been unknowingly issued to others.

- *Stores management notified of chair being ready but equipment has been used for another user (Focus group 2)*

When the service user has been able to give very detailed information about what they believe needs repairing, the engineer has sometimes subsequently turned up with the wrong parts. Some complain of equipment not being regularly maintained and/or tested properly after a subsequent repair; others criticise the unavailability of parts that could help to repair damaged chairs.

- *No parts, can't repair some chairs (Focus group 1)*
- *Chairs not tested properly after a repair (Focus group 2)*
- *There's no regular maintenance; there's some maintenance when the engineer is there fixing something else (Focus group 1)*

Consequently, instead of repairing chairs, respondents believe Millbrook are actively choosing to place some service users back on waiting lists for new chairs because of their inability to fix the problems.

- *Instead of repairing some chairs putting service users are being put back on waiting list for new chairs (Focus group 2)*
- *The centre of gravity of my chair needs adjusted. Instead on adjusting the centre of gravity, they have put me of the waiting list for an assessment for a new chair. The chair I have could be fixed. (Focus group 1)*

Respondents do acknowledge that some parts are genuinely unobtainable and service users really do have no alternative other than to go back on a waiting list for a new chair. They fear being placed back on a waiting list and enduring more uncertainty.



- *I can't get my chair fix as they don't make the parts anymore so I'm now on the waiting list an assessment for a new chair. I have no idea when I will be assessed (Focus group 1)*

Indeed, none of these shortcomings takes into consideration the effect on these vulnerable service users own personal circumstances which can be considerable given their disabilities.

- *Need to take into consideration a service users' personal circumstances - it can be an emergency if the service users lives alone and doesn't have a carer coming in (Focus group 2)*

Most respondents claim they have never seen or been asked for feedback about the service through surveys despite being told that evaluation forms are often left with service users.

- *Have never been asked for feedback - told surveys/feedback forms are left with service users but never seen one (Focus group 1)*

Communication

Respondents complain of difficulties communicating with Millbrook via telephone. Respondents also mention that Millbrook failed to sufficiently share the new phone number when they got the contract.

- *It can take 15 minutes to get through. (Focus group 1)*
- *The phone service has gotten better but still variable (Focus group 2)*
- *Often difficult to get through, It has got better (Focus group 1)*

Communication via e-mail on the other hand is perceived to be slightly better but response levels are still seen as variable.

- *Auto message says leave a message - pointless, no one responds (Focus group 1)*
- *They don't get back to you (Focus group 2)*
- *I never leave a message as they never phone you back. (Focus group 1)*

Respondents mention promises are made by Millbrook either to return calls and emails, or to action agreed upon responses, but they often fail to materialise.

- *They say they will return calls, they don't. Often ask for the name and position of the call taker so I can follow-up (Focus group 2)*
- *No response to three e-mails (Focus group 2)*





Subsequently a number of respondents feel the need to confirm the outcomes of successful calls by e-mail so there is an audit trail

- *Never get acknowledgements (Focus group 2)*
- *If you don't chase, nothing happens (Focus group 2)*

As a result of the above, communication within the organisation is widely perceived to be inadequate.

- *Different departments not talking to each other (Focus group 1)*
- *Different information from different members of staff (Focus group 2)*

Although some call handling staff at Millbrook are seen as helpful, others question the attitude and experience of operators.

- *Do the phone operators understand wheelchairs? (Focus group 1)*

For example, some customer services at Millbrook are seen to withhold details of therapists. Whereas others complain that customer services are not very responsive: rapid telephone triage for priority cases does not happen they say. Indeed, a common sentiment expressed was that it was an effort to get any useful information whatsoever.

- *Duty OT useful but very difficult to speak to (Focus group 1)*

Others complain of inferior complaint handling processes and serious safeguarding concerns.

- *I know of an urgent, high level concern featuring someone who was unable to leave hospital, their skin being damaged; they developed pressure sores and this did not get a timely response (Focus group 1)*

Administration

Concern was expressed that Millbrook does not have complete electronic records for all service users.

- *When you phone up they ask you what wheelchair you have. Don't they know? (Focus group 1)*
- *Is there a database of equipment or any records? Does this exist pre-Solent? (Focus group 2)*
- *No documentations attached to patient notes after assessment - resources? (Focus group 2)*

Subsequently, the lack of service users' records is seen to increase uncertainties and impede the work of the Occupational therapists who then conduct the assessments.

- *Where are the detailed reports provided by therapists going as they haven't been seen by the OTs doing the assessments and are not available at assessment? (Focus group 2)*
- *You don't know where you are in the process. (Focus group 1)*

There is some suggestion that not all records were transferred when Millbrook took over the contract and that Millbrook has been trying to build up a database of service user records ever since. Respondents also complain of a lack of ongoing updates and the shifting of responsibility back to service user or referrer.

- *No details of wheelchairs (prior to their contract) (Focus group 1)*
- *Lack of historic data from when Millbrook took over the contract. (Focus group 2)*
- *Do they know what equipment we have? (Focus group 1)*



Feedback and findings: Part Two -

In-depth interviews with service users and carers

Between February and March 2017, Healthwatch Hampshire undertook 24 in-depth telephone interviews with service users and carers. Participants included a range of adults, parents of children, people with both neural and spinal conditions and people with both powered and manual chairs.

The 'Discovery style' approach was used as a basis for the approach to each interview. The technique is aimed at eliciting patient stories and is a relatively open process but held together by a 'spine' of themes/topics/prompts that the interviewer uses to ensure that all of the important aspects are covered. For more information about the approach please see:

www2.rcn.org.uk/downloads/professional_development/mental_health_virtual_ward/treatments_and_therapies/chd-discovery-interviewspdf.pdf

The interviewer began each interview with the following statement:

'We would prefer you to tell us your story in your own words with as few interruptions from us as possible, but we do have some prompts to help guide the conversation if it would help. Let's start at the beginning, tell us your story in your own words...'

We then used the following spine to prompt/guide the conversation as necessary:

- Referral
- Assessment
- Updates & Communication (to include website/phone calls/written comms)
- Repairs and Maintenance
- Waiting times
- Wheelchair (to include suitability/meeting expectations/satisfaction)

All participants gave consent to take part. The details of individuals have been anonymised but where appropriate details are given about participant's sex, condition and wheelchair. Direct quotes are in italics.

Referral

Although a few respondents were satisfied with the referral process, most were frustrated by the experience.

- *I think the referral process was about two months. It was much quicker than I anticipated. (Female, child, cerebral palsy, manual)*
- *No I didn't have to wait a long time. The doctor saw to it for me - the doctor requested it. (Female, adult, orthopaedic, other, manual)*
- *Millbrook Repair engineer advised child with a long term condition had outgrown their electric chair and a new one was required. On telephoning the service to request an urgent appointment for measurement for a new chair she was told her son had to be re-referred to wheelchair services. This was a long process including the community paediatrician having to send a letter. It was frustrating and even the consultant thought this is crazy.*



- *...it was about eight months to get the self-propelled one, which I thought was an awfully long time because I had already waited for my first chair. Why do I have to wait, I'm only swapping over.*

The majority were unhappy both with the length of time they had to wait to receive a referral for a wheelchair and also the lack of updates coming from the Millbrook office team.

- *The wheelchair took a long, long time to arrive. (Adult, male, auto-immune disease, manual)*

The dissatisfaction at times led some respondents to take the issue into their own hands. These particular individuals felt that there was no alternative but to raise a complaint which resulted in an immediate resolution in some cases.

- *If it wasn't for me chasing and making a complaint about the rudeness of some of their staff and asking to speak to a manager suddenly the wheels started turning and I got an appointment! (Mother of child, female, Ataxia, manual)*

However, others were less fortunate. Their enquiries were placated with sometimes ambiguous promises and / or told to 'just wait'. In some situations, it appears respondents who had raised concerns were told that they risked being returned to the back of the queue if they persisted in contacting the office for any updates about their referral.

- *I put in a request and was told that there would be a wait and we weren't to contact them to find out where he is on the list because if we do he will either go to the back of the queue or we won't be seen. (Spouse of Adult, male, MS, powered)*

This caused those individuals in particular, who were already feeling a sense of injustice and confusion by this stage, increasingly more helpless. It was not knowing what was happening or being able to influence matters that frustrated them.

- *I feel we are always made to feel as if we are being a nuisance and that there are people worse off than my husband but he is pretty bad. It is just waiting all the time. It makes life more difficult. I don't think their service is very good and I know they have had lots of people leave. (Spouse of Adult, male, MS, powered)*

The length of time many of these respondents had to bear the uncertainty around their equipment was occasionally significant and only acted to exacerbate their anxieties further.

- *I had about six months of waiting and I had to get them to recognise that a referral had been made. That was quite frustrating. Then within two or three months I heard from them by letter. From that point it took a further year with me making phone calls and e-mailing them to tell them that I was in real need of a new wheelchair. Then I didn't hear anything for six months! It was an ongoing saga! (Adult, male, quadriplegic, manual)*

Service Users can also find that what they might have requested on referral does not actually meet their life needs.

- *It was a mistake but I had to find out for myself by having an electric wheelchair...it was so big. My self-propelled one is a lot easier for me. It is not so bulky and I'm fine with it.*





Assessment

The assessment process on the other hand was a far more encouraging experience for many of these respondents. Respondents were generally positive about the assessment service.

- *When we did see them we had very good service. They were very good at working out what we needed and very helpful.*
- *It is a fine balance between J being comfortable and ensuring good posture. When X's seating hasn't been right it has caused hamstring problems, which he has problems with anyway*
- *My first experiences I was very nervous and that disappeared within moments because the representative (of Millbrook) we met over at the workshop (Havant?) were absolutely superb. He was very calm, very professional and very fun. My daughter wasn't at all nervous. He immediately got the gauge of my daughter, got her relaxed, got her talking, got her excited. From then on I thought this whole experience is going to be superb. He was very much able to combine his professional opinion of what my daughter should have with her ideas such as colours of wheels, colours of frames. (Mother of female, child, cerebral Palsy, manual)*
- *(At the assessment) she was wonderful. There were two people there and she was really good. (Father of child, male, cerebral palsy, manual)*
- *After making a formal complaint and suddenly getting an appointment 'out of nowhere'; from then on I must say that when we went to the appointment that went really well. The guy who did it was really good. Gave us all the information. He assessed her. We got a pushchair buggy. It is everything she needed. We are using it all the time for her. So once we got off the waiting list and got an appointment it was really good. It was fine. (Mother of child, female, Ataxia, manual)*



However, there was an observation amongst some respondents that this was in spite of the perceived wider failings elsewhere in the organisation.

- *The only thing is I think she is torn in several directions. I think she has lots of work on her hands. She seems to see so many people. But she is absolutely brilliant. (Adult, female, MND, powered)*

There were a few respondents who were not happy with the assessment process however. Some had experienced issues where Millbrook had identified incorrect assessment but had subsequently taken steps to correct this.

- *X (child) was assessed in September. In October Millbrook called to say that the wrong person had measured him and an appointment to be re-measured would take place in mid-November, causing a further 8 week delay for a child already in significant discomfort.*

- *They overestimated my needs but I suppose that is a good thing rather than underestimating. It was trial and error. They did say they can't solve all my problems but they would try and solve some, which is*



what they have done.They have done a good job. They have given me what I asked for a chair that goes back a bit so I could ease my hip when it got a bit tight.

Some people felt patronised because they did not feel listened to during the process, however they are in the minority as most people were pleased overall with the assessors and the assessment process.

- *When I was being interviewed (assessed) it was like I wasn't being listened to and they were trying to tell me what I needed. (Adult, male, quadriplegic, manual)*

Waiting times

Service Users did not know what to expect from the service regarding contacts or waiting times or were given inaccurate information.

- *I didn't know how long it would take to get a chair. When I was chasing it up they couldn't give me a delivery date.*
- *The family were told it would take 8 - 10 weeks for the new manual chair and it actually took 27 weeks.*
- *When I got through to Millbrook some people said they didn't know what was happening with my wheelchair or how long it would take. I got all sorts of answers like it's in Germany being modified and another person said I don't think it had been ordered yet. I got all sorts of mixed messages from them.*
- *A temporary repair was made to dangerous foot rest gap, but makes life difficult and is not thought to be a permanent arrangement. The respondent does not know if an alternative solution is going to be provided or when.*

The majority of respondents were deeply unhappy at the length of time they had to wait for a chair to arrive.

- *The wheelchair took a long, long time to arrive. (Adult, male, auto-immune disease, manual)*
- *We have dealt with Millbrook as you know. The waiting time is just awful! (Spouse of adult, male, MS, powered)*
- *As for the wheelchair the wait time was absolutely ridiculous. We waited seven or eight months before we got it after it was requested. (father of child, male, cerebral palsy, manual)*
- *It was quite a long wait from when we were referred until we saw someone,then of course we had to wait for the wheelchair and that took another couple of months and we had to phone them up to check what was happening. I think from start to finish the whole thing was about eleven months. It was quite an issue at the time.*
- *X has been waiting (over two years) for a powered chair - 'I'm in line to have an electric chair but I've not had any word on that all.' 'An electric one would help me in the long run, later on. It probably would help me.'*

Most of these respondents who were eager to understand why their particular wait was taking so long, stated that they contacted Millbrook to seek answers only to be pacified by often contradictory and/or ambiguous replies.

- *It was just the waiting to get that appointment. I kept on being told they would assess the list to see if I could be pushed up the list at all. No-one ever got back to me. No-one came back to me. It was hard to get through on the phone. We deal with physiotherapists, occupational therapists, various doctors, hospital, GP. I wanted to do this survey because I want people to know that the process is so bad. I had also had feedback from other health people that it was renowned for a) quite a long waiting list and b) not a particularly helpful service. (Mother of child, female, Ataxia, manual)*

- *They promised that the harness would be changed in about a week but it was about three months! The second was when the guy at Millbrook promised me that in a week's time they would change the headrest. And the headrest was changed nine months later! (Father of male, child, cerebral palsy, manual)*

Indeed, waiting times can cause physical and emotional distress to service users and their families.

- *X got to the point that she didn't know what to do anymore. It was so upsetting because her son was squashed in his chair all day. Her son was getting so upset and was telling his mum he was so uncomfortable. Her son was getting backache and when he got home from school he just needed to get out of his wheelchair, but he didn't want to get out of his chair as that is how he moves about.*

The impact of the uncertainty around their chairs and the indeterminable waiting time, left many respondents mentally and in some cases more physically exhausted by the ordeal as they sometimes had to cope without appropriate equipment in the meantime.

- *The impact of their (Millbrook's) failings have been quite serious on X. She has spent many more months in bed when she need not have done so if Millbrook had done things properly in the first place. (Adult, female, MS, manual)*

Only a very small minority of respondents were satisfied with the waiting times for their chairs. Of these, most were pleasantly surprised with the length of their wait. Many of them had expected and braced themselves for a longer wait such was their low expectation levels.



- *He gave us, a timescale of when the wheelchair would arrive. I said to my daughter it is probably not going to be before September (summer holidays 2016) but it will be there for September so you can start a new academic year being more independent. It arrived way before that in the summer holidays so we were able to practice in it so she was able to get used to it, familiarise herself with it and it really has been a brilliant success story. (mother of female, child, cerebral palsy, manual)*
- *I can't remember how long it took (for my chair). It came sooner than we had anticipated. We were told it would be quite a few months and then it came earlier than expected so I was delighted (2015). I was absolutely thrilled to bits. (adult, female, MND, powered)*
- *I think it took four months and the wheelchair arrived. And that was all excellent. It all went well. (adult, male, MND, powered)*
- *The whole process took a long time, we were waiting months for his assessment and then for the chair. (Mother of child, male, global development delay, manual)*
- *There has been a massive improvement in the last year. It only took a couple of months to X's last chair, which he has had about 10 months. In the past it took much longer 9 - 10 months.*
- *The third wheelchair arrived quickly.*

Wheelchair (suitability/meeting expectations/satisfaction)

When wheelchairs did arrive there were mixed reactions from people. Some respondents were pleasantly surprised by the chairs they received: happy with both the relatively short wait and also the quality and style of their chairs.



- *It absolutely meets her needs perfectly. It is great because when she goes on a school trip it folds down and the colours are so stylish, they are just my daughter's styles - pink, yellow, blue. It is absolutely perfect because she feels very proud and almost privileged to be able to have one. (Mother of female, child, cerebral palsy manual)*
- *No problems at all. Its (the chair) is lovely. (adult, female, orthopaedic, other, manual)*
- *What I can say is that despite the year and a half wait they did supply me with a reasonable chair for my home and going to the local shops and things like that. (adult, male, quadriplegic, manual)*
- *I think I got a letter and I went to Hampshire services in Southampton to test drive a wheelchair and the order went in. It proceeded very well. I think it took four months and the wheelchair arrived. And that was all excellent. It all went well. (adult, male, MND, powered)*

Some respondents explained how the wheelchair they received gave them a new sense of freedom, independence and empowerment; for those fortunate individuals their expectation levels were met and also exceeded.

- *Both from my daughter's terms and the actual equipment that they supplied was just spot on for my daughter's needs. (female, child, cerebral palsy, manual)*
- *It has definitely made a difference as my daughter can take me out in the car and they take the chair with them and then I can go around the shops and that with them. I can't walk around the shops no more. It is lovely, as I've been able to get out more. (adult, female, orthopaedic, other, manual)*

They were also positive about staff efforts to ensure that the chairs were modified if necessary to meet their needs. In some cases, staff had been pro-active about checking that the chair did meet their needs - this was key as some service users are reluctant to raise problems.

- *They phoned up after a couple of months to see how I was getting on, which I was quite pleased about because I didn't like to phone them up to say I wasn't happy with it....I was really pleased with they followed it up to see if we were alright. I was relieved really.*
- *The lady came out and looked at the problems that we had. She suggested that if we come in to them she had a few ideas so we went in and saw them. We tried out various things. In the end a couple of changes made it fine and we were really happy with it.*

They were able to raise issues with existing chairs with the service.

- *X's current manual chair is causing him some physical problems. His feet push out and putting his feet on his footplates causes one of his legs to rub against the leg of the wheelchair. X has rubber stoppers to stop his legs hitting the bars and is waiting for an appointment to see what they can do about that.*
- *My arms are weak and I felt that in some circumstances my arms would fall off the armrests and I would lose control of the chair. So I've had special gutter armrest fitted to it. Millbrook sent someone out to my premises to do that. I had to tell them about it.*

However, it is not clear that all significant issues are raised with Millbrook or community care teams.

- *The chair I've got is no good for my spine. I've got a twisted spine and it is putting pressure on the bottom of my spine. It was not clear that this had been raised although leg rubbing issues had.*

Some of these respondents resorted to using private companies to source adaptations to their chairs.

- *The current power pack isn't strong enough so the family has just ordered a new one, which is costing £1000 but it is not going to be a good fit of the type of wheelchair X has now. The family aren't sure if they will be able to fit the stronger power pack.*



- *I've had a mobile arm rest bracket fitted to wheelchair back so when I go out I can put my right arm in the arm rest and feed myself.*
- *When the repair man came out he noticed the family had replaced the gel pads on the arms of the wheelchair. Mr W had sourced the gel pads from the internet and his father had fitted them to his wheelchair. The family didn't know that they could phone and that the wheelchair service would do repairs.*

Unquestionably though, delivered chairs do not always meet the specification from the assessment, leading to further delay and unmet need. This adds to the frustration where there has been a long wait for the chair. In some cases, this is linked to prolonged interval before chair delivery during which there has been a change in service user condition. Families may go through several cycles of waiting for a different chair before need is met.

- *They took all the instructions like he had to have the controller on his left hand side and a rest for his right arm. About six months later they turned up with it and all the controls and the arm rest were on the wrong side. The poor man had to try and change it all over. On the control side there was this big black bit sticking out into my husband's side...and his legs weren't comfortable. It just didn't work out.*
- *The demonstration wheelchair they brought out to me in April was much higher than the one I received so I automatically thought it would be the same type of wheelchair, with the same features on it that I would be getting but it wasn't.... I knew right away I couldn't sit in it. It was too low.... I couldn't use it. We then had to wait several weeks for them to come out and fit a riser kit to it....It was a major disappointment.*
- *X was assessed in July 2015. A wheelchair arrived in April 2016 but it was considered by the OT to be unsuitable: X had put on a lot of weight from the time she was assessed. A second chair was delivered in June 2016, by which time X was having problems standing and getting up and down. Further modifications were needed to deal with this and weight-related chair sag.*
- *The footplates on the new chair (February 2016) were too low so (child's) feet couldn't reach the footplates and their feet and legs were just hanging. 'It was just awful - it really was.' The arm rests were too low as well so he started to get weakness in the arms too as his arms weren't resting on anything. The carer had to contact Millbrook. Arm rests were fitted in April 2016 but the footplates had never been ordered as alternatives could not be found. So the technician just went away and chopped a bit off to make it shorter and the right height.*
- *A tray was requested in April 2016 to enable a child to drink. A tray provided in May 2016 did not fit and had to be taken away for modification. In October 2016 a tray was dropped off; the carers could not fit it; in November 2016 an engineer visited and confirmed it was not suitable for the chair. In February 2017 engineers altered the tray on site to just fit but recommended a different tray is needed.*
- *The one before that wasn't suitable because I couldn't propel myself in it. I live on my own. I waited about a couple of months for my first chair. Then I chased OT up and said 'this is not suitable' then it took several more months to get this one delivered and I've had this one about six weeks. I notified OT about it and she said she would chase them up. She sighed as if she had had a problem before. It is just the timescale making life difficult to be honest. (adult, male, auto-immune-disease, manual)*

In the short term this meant that some respondents either had to endure some physical discomfort as well as practical shortcomings, but ultimately it often meant for some of them further inactivity, further isolation and further loneliness as their lack of mobility dictated.

- *When it arrived I couldn't propel it, I live on my own. I don't know who didn't pick that up, whether it was the OT or the wheelchair people. I got the wrong thing. (adult, male, auto-immune-disease, manual)*



Those respondents, who out of desperation, did manage to venture out with the incorrect equipment often risked some personal danger. The temporary and unsatisfactory alterations personally made to their chairs to enable them to go out and about, often were masking larger, fundamental technical faults. Some of which negatively impacted upon the balance and manoeuvrability of the chairs which sometimes resulted in falls and in one instance in particular, a subsequent hospital visit.

- *I was sat in it and I twisted round to talk to someone and the front wheel thing broke off and I fell out. I had also out of it at Tesco's when my son was wheeling me across the car park. There was a little raised drain, they have solid tyres and bang. He fell on top of me. It might be the quality of them. (adult, male, auto-immune-disease, manual)*

Nevertheless, the temporary fixes imposed upon these respondents often resulted in a lack of independent mobility because the faults with the equipment meant they could not manoeuvre themselves without needing additional carer support. This subsequently left these respondents in particular, extremely unhappy, further irritated and again further isolated.

- *I was sat in this chair and I thought I am getting a bit uncomfortable so I tried to manoeuvre myself to get up to sit in a more comfortable chair and I ended up on the floor. The handbrake had pulled off on this thing and part of the plastic bracket at the back had broken. As a result of falling there I was in hospital most of yesterday and I had the paramedics here for a couple of hours deciding what to do with me. (adult, male, auto-immune-disease, manual)*
- *After many, many trials and many, many months of waiting and waiting they eventually provided this chair with the new seating. But the chair itself has small wheels. But where Mrs G can be out of bed she can't move herself. So if I am not here, and I make sure this doesn't happen, she can't move until I or one of her carer's gets back. She has no mobility whatsoever. This has been pointed out to them but they say it is difficult and that is the end of the story - 'Their problem not ours'. (Spouse of adult, female, MS, manual)*

Some respondents had a particular complaint about the quality and design of the wheelchairs they were provided. They were perceived as cheap and not particularly robust which affected their mobility and comfort to such a degree that it was felt to have an adverse effect on their quality of life.

- *The only wheelchair we were offered is this clunky, geriatric wheelchair that doesn't allow him much speed and flexibility by himself. It is fine. He doesn't have much. He takes what he is given. He is very*



happy but I just think if he had the option of something different it might be a different experience. (child, male, cerebral palsy, manual)

- *No my wheelchair is not comfortable, not really. I am sitting down on it. I don't get a sore bottom but I just can't sit in it properly. (adult, female, cerebral palsy, manual)*



When they did attempt to raise any concerns, many respondents were often met with either an indifferent and/or confused response. For example, it was not uncommon for these people to mention to researchers that the confusion sometimes resulted in unannounced visits and/or frequent deliveries of the wrong parts or equipment. Either way, this confusion resulted in further waits and also further annoyance.

- *They ordered the parts twice and they weren't the right parts. This went on for a couple of months each time. (adult, male, MS, powered)*

A significant number of respondents subsequently regarded the Millbrook service in rather disapproving terms. There was a tangible sense of anguish, apathy and also sadness because the service was in some cases perceived to be failing the people who need it the most.

- *X is not independent. She is dependent on other people. The whole situation is shambolic. There seems to be little care for people. Some of the loss of independence is down to not having the right wheelchair. (Spouse of adult, female, MS, manual)*
- *"Whenever I say wheelchair services everyone does a groan. It is so sad that it is the kids who are suffering. I hate to hear it. You don't know what is happening and you do feel forgotten about."*
- *"I think they are doing the best that they can. It is hard to know. Something is wrong. I am tired of it. I want to concentrate on my (child) and not worry about wheelchairs."*

In conclusion, most respondents initially had very realistic expectation levels about the service they would receive from Millbrook. They were aware that the wheelchair service - like many other agencies within the health and social care environment presently - would probably be affected to a certain degree by local government's budget cuts and that the service would be compromised accordingly, however, few expected service levels to drop as much as they were perceived to. The apparent levels of incompetence truly surprised many of them.

Repairs and Maintenance

When repairs and maintenance was required on their wheelchairs, a few respondents were pleased overall. These individuals, although overwhelmingly in the minority, were satisfied with the quality of the maintenance and repairs and also the fast pace of them.

- *When we have needed footplate adjustments the mechanics have been quite good at coming, getting out and fixing things. They have been quite good on the whole. (adult, female, MND, powered)*
- *I've phoned them up as there was something wrong with the back wheel but that has all been fixed now. I didn't really have to wait a long time for them to fix it - a couple of days. (adult, female, cerebral palsy, manual)*

However, again, the clear consensus amongst people was that the overall pace, regularity, quality of repairs and maintenance was poor.

- *It is a long process to try and get the chair fixed. They will come and pick it up one day, then it is on the van all day to it gets to the workshop and then it gets worked on the next couple of days, then it is another day to get it back again. Four days doesn't seem a long time but it is if you are in an electric wheelchair and it's your independence. It gets you so down. It's heart breaking. It is so upsetting.*
- *I was thinking about putting a softer cushion on it. When you have been sat in it quite a while you get a bit stiff. (adult, female, orthopaedic, other, manual)*
- *It is about three and a half years old and it has only been maintained about once. (Manual Chair)*



Either the equipment was essentially the wrong type to be issued in the first instance.

- *This chair has almost tipped twice going into a little chinch in the road. A tiny little curb change and if the wheel is not in the right direction it has almost tipped twice on me while I was pushing it. The centre of gravity is completely off. The front wheel is way too small and it is way too close to the big wheel. That is my opinion. I am not an engineer but it is obviously not right.*

Or, the overall build quality was perceived to be inferior and not robust enough to withstand daily use by a disabled person.

- *I need a new back on it to keep me upright because I am falling over to the side. X is bringing a new back for me so I can try it out. I think she is going to bring two to see which is the most suitable. (adult, female, MND, powered)*
- *It is still wobbly. We have learnt to live with wobbly. (Adult, female, MS, manual)*

Some respondents were not even made aware that the wheelchair service provided a repairs and maintenance service.

- *The family didn't know that they could phone and that the wheelchair service would do repairs and had made repairs themselves. They had no number until it was provided to them during a respite stay. They phoned about a footplate that came off his chair - it was repaired the next day.*

Indeed, there was an impression amongst a few respondents that a number of these issues stemmed from a lack of coordination. Once a few respondents managed to bypass the office and talk directly to the staff in the workshop about their chairs, were they able to reach a satisfactory resolution, they claimed.

- *Unfortunately, I have had two bad experiences with Millbrook. First time my son's harness was broken and the second the headrest was unsuitable for my son. (male, child, cerebral palsy, manual)*
- *When you talk to the Millbrook office they don't know what they are doing it is so frustrating so I went down the workshop and the engineer fixed everything. He did properly what should have been done eighteen months before. I have got to the end of my tether with them. (adult, male, MS)*

Interactions with staff, updates and Communication (web/phone/written)

There were some positive comments made by respondents about the updates and communication they received. Service users were generally positive about the attitude and helpfulness of staff in face to face interactions (principally with OTs and engineers).

- *The OT and the technician who came out with her, were absolutely wonderful*
- *I would say what they did do was make everyone feel at ease, enthusiastic. Things that wasn't part of their job description they went above their role by reaching out to people like my daughter and me because I was nervous and apprehensive. (female, child, cerebral palsy, manual)*
- *The delivery guy was fine, nice and friendly. The girl in the office I spoke to was friendly. It just seems to me to be rather inefficient. (adult, male, auto-immune-disease, manual)*
- *I felt they went above what was needed and certainly what was expected. It wasn't just a technical situation - it didn't feel as if we were there to be measured. It wasn't this size will fit you it was about lets get excited about, lets feel that my daughter is making a connection with it beforehand so that nothing was frightening when it turned up. It was exactly as she remembered the colours, the spoke. guards, the colour of the frame. It was just real excitement. It was like Christmas - there was this thing that would enable you to do something. (female, child, cerebral palsy, manual)*



- *She (mother) feels she is listened to now and that communication is much better. In the past she didn't feel listened to by the wheelchair service.*
- *When we were waiting the first time we didn't really know who to phone. Once we got the number we waiting a couple of more months then we phoned up again. We knew who to phone.*
- *There was one really helpful lady - I don't know who she was.*
- *I have their phone number. I can phone them up if there is there are any problems. They did say if there are any changes just to give them a call.*
- *The ladies at the appointment were lovely. A lady, who has since left, promised to get it sorted out and that she would do everything she possibly could to get it fast forwarded.*

Nevertheless, a common sentiment expressed by respondents in the study was that the administration, coordination, updates, communication and indeed, customer service levels, fell short of expectations. There was acknowledgement that Millbrook staff on the whole had good intentions but the service was being adversely affected by other internal issues.

- *The people you see are nice and aren't horrible at all. They are trying to help but just getting through these processes is a nightmare.*
- *She said a suitable wheelchair was in and they would let me know when they were going to deliver it. But that still took a while to be delivered. No feedback from them. (adult, male, auto-immune-disease, manual)*
- *I contacted them because we received a letter saying they had received the request for a wheelchair - the request from the physio. Just so you know we have received it so I called back a few months later to say I had received this letter but nothing had happened and they just said you have to wait. We have the referral and you just have to wait. (child, male, cerebral palsy, manual)*

Contacting Millbrook (by phone and email) was perceived to be a difficult and frustrating experience. Service Users want to be able to speak to those involved in providing their chair/repair. Allied Health Professionals supporting service users also expressed frustration.

- *When you phone up you just get the receptionist.....you don't get a chance to speak to any of the mechanics. Then you get all rigmarole about monitoring. Why they have to do all that I don't know.*
- *Communication with Millbrook was absolutely terrible..... They would say they would phone you back with an answer but they never did. If they said they would phone back 9 times out of 10 they never did so I was on the phone again the next day chasing them.*
- *X tried to contact [named clinical staff member] by phone, leaving messages and by e-mail but was unable to do so.*
- *A lot of times when I've phoned up you can't really get anywhere. Nothing seems to be happening. I've e-mailed them quite a lot. That way I have an audit trail and I know the dates.*
- *I phoned them up a couple of times and they just put the phone down. Then I went to my OT and she had the same problem.*
- *They would say they would get someone to phone you back but they never did.*

Frequently throughout the research, interviewees mentioned that they had been promised updates but nobody at Millbrook bothered replying to them, they explained. As it was, they were frequently left wondering what was happening.



- *I asked on several occasions if they could give me an indication of how long it would be before we were seen and nobody got back to me. (Child, female, Ataxia, manual)*

Service users were frustrated by visits taking place without warning, or where times were miscommunicated, which lead to were significant inconvenience and/or sub-optimum communication with stakeholders in service user's care.

- *About four months later without any notification, when I wasn't there they turned up at the home ready to re-adjust everything. They never phoned up to make an appointment otherwise I would have been there.*
- *X was waiting at school at 10.30 but the man had been told the wrong time and didn't come until 1.30. X was waiting all that time at school waiting for the tray. X just didn't want to miss it.*

At other times when the uncertainty surrounding their chairs became too prolonged, and they had no alternative but to contact Millbrook for an update, some respondents explained that they were often courteously placated with a promise to do something only to be let down subsequently when the agreed upon solutions and actions failed to actually materialise.

- *I had a meeting with Millbrook and X told me we will fix it immediately. "It is awful the way you haven't got this table top". Absolutely nothing happened. Two weeks later I phoned them and she said 'I don't know anything about that.' (Adult, female, MS, manual)*



- *The staff individually are very pleasant but I don't believe anything they tell me. They will tell me anything - one example of that was when Mrs G chair was delivered without a seat David who delivered it said he would make a phone call right away but disappeared down the road, nothing ever happened. To your face they are very pleasant but in fact it doesn't happen. (Adult, female, MS, manual)*

In this regards, service users felt that they might be perceived as a nuisance because they repeatedly had to chase for updates from the service.

- *I feel as if I am always nagging at them. I don't want to be a pain. All the people I've spoken to are polite. They aren't rude. It is just the system. It is not working at all. It really isn't.*
- *When you rang up Millbrook Healthcare, I just don't know I wouldn't say they were that helpful. They would be 'oh it's them again, a pain in the bum.' I don't care. I will keep pestering until I get what I want.*

Things reached such a nadir that commonly, Millbrook was either perceived as incompetent, negative, insensitive and in some instances openly condescending towards them and what they represented.



- *They don't keep you updated to how much longer it is going to be. You don't know if you have been forgotten or whether you should phone. It is very difficult. (adult, male, MS, powered)*
- *There was a bit of a lack of communication. I sent several e-mails and phone calls. There appeared to be a miss-mash of communication. (adult, male, MND, powered)*
- *I didn't get a feedback form. I would have given an honest opinion I was that angry with them at the time. They didn't handle my complaint at all. I asked to speak to the manager and I asked to be called back that day. I didn't actually speak to the manager. I didn't get a call back but I got the letter with an appointment in the next one or two days so I thought maybe me threatening saying I wanted to take this further kick started a letter to me to kind of appease me. (Child, female, Ataxia, manual)*
- *My impression is that there is a bit of an organisational management issue that needs tightening up! (adult, male, MND, powered)*
- *His teacher last year phoned Millbrook a few times about how the harness was very bad - It was rubbing my son's neck making it red and sore. There was no quick answer to his problem from Millbrook. (male, child, cerebral palsy, manual)*
- *It was hard to get an update or know exactly what was going on. It is alright to get to like a receptionist or an admin type person but you are not entirely sure they know the situation. Basically you don't get to speak to who you need to speak to, the person doing the assessment. (child, male, global development delay, manual)*
- *When you talk to the Millbrook office they don't know what they are doing it is so frustrating so I went down the workshop and the engineer fixed everything. He did properly what should have been done eighteen months before. I have got to the end of my tether with them. (adult, male, MS)*

A solution to the above problems volunteered by one respondent was for the Millbrook service itself to consider actively employing more disabled wheelchair users. This would serve many purposes not least seeing things from the user's perspective and truly understanding what the wheelchair represents to each individual. This would undoubtedly help to improve the Millbrook service, they suggest.

- *If you phone up Millbrook they just can't do it. Their attitude is so, so negative. That is the difference apart from the lack of experience and the lack of knowledge. I would put guys or girls on reception who are in wheelchair. Stick them on reception so when people phone up they know what they are talking about. We could do a much better job.*

Respondents did not mention the Millbrook website. It was not apparent that they were aware of this or found it a useful source of information. Respondents also had not received feedback forms at either chair hand-over or following repairs.





Further comments:

Chairs and Living Environment

There can be a mismatch between chairs and the living environment; including the provision within care homes.

- *The rooms of the care home are small and they didn't really take into consideration the space needed for a hoist and the powered chair in X's room. It was difficult to use the hoist to manoeuvre X into his powered chair. When X is in bed, their wheelchair is kept in the bathroom. It wasn't easy to move the powered chair into the bathroom. About the only way to do so was to sit in it and drive it into the bathroom, which the girls didn't like doing. They were very cross when they had to take the chair away.*
- *The care home does have transfer chairs but they aren't large enough for X. He wants to go out. Even into the garden for a bit of fresh air. It would be good to bring him up home occasionally. The front wheels of the chair he has now have been made wider than the back. My doors were altered and the home has wide doors but he can hardly get it through. It keeps getting stuck in the doorways. The staff, of the care home have tried taking him out but his large manual chair got stuck. I don't know what they would do if he had to go into hospital - probably a stretcher. I ought to ask if he can have a 'transporting' wheelchair again.*
- *I can't use it here. I can't get out here because of the steps. (Respondent is waiting to move from their own home into sheltered accommodation)*

Needs of care providers impact on usability of chairs.

- *When Mr X went into a care home, the home suggested a powered chair so Mr X. could get about the home and be more mobile and because the 'girls' found it difficult to move him around.*

Impact of joint working with Care Homes

Liaison between Care Homes, Millbrook and families can enhance care but is not always effective.

- *I reported it to the physio department, who are the ones who now deal with contacting the wheelchair clinic to ask that it be dealt with urgently because it was dangerous. There was a wheelchair clinic the following week.*
- *The staff had been complaining about the weight of X in the chair and the current power pack. The family has been told to contact Millbrook directly but it doesn't really work.*
- *X (carer) was advised by the physiotherapist at the care home to contact the Millbrook OT directly.*
- *Someone from Millbrook comes (to the home) once every two months..... then you have to wait after that (the clinic) for whatever is necessary. It is ridiculous.*

Impact of joint working with Special Schools

The special school X attends has physios and OTs so he is having regular reviews at school now rather than waiting until he has a growth spurt and then they realised his chair or moulded seating was too small for him. It is much easier now that the school is involved and everyone is communicating.



Recommendations

Based on findings from both the focus groups and service user interviews, Healthwatch Hampshire have compiled the following recommendations for Millbrook Healthcare and West Hampshire CCG. These recommendations have come from service users, carers, stakeholder organisations and professionals that regularly refer into the Wheelchair service. The recommendations are included in full below. A summary of these recommendations is included at the start of the document.

Most respondents are of the opinion that the contract model in its present form is flawed - It was felt there is not enough money currently to provide a decent, well-resourced service.

- **Use a different contract model, which enables the service to be better funded. There is not enough money currently to provide good service. (Focus group 2)**

Some focus group participants suggested merging the equipment and wheelchair services together as the equipment service is perceived to be the more effective.

- **Merge the equipment and wheelchair services as the equipment service seems to be working. (Focus group 1)**

Others people suggest the service improve their communication with referring agencies to help improve the service.

- **Share full referral criteria (criteria for seating, manual wheelchairs and power chairs) with referring agencies. (Focus group 2)**

In terms of Millbrook acknowledging and confirming referrals - which was widely criticised throughout the study - respondents suggest a number of solutions. One suggestion involves ensuring Millbrook employs an NHS.net email

address, which would enable referring agencies to send referrals by e-mail. It would then be possible to confirm receipt of a referral via an automated e-mail and help to improve the audit trail and subsequently, Millbrook's administrative burden, they say.

- **Ensure Millbrook has and uses an NHS.net email address, which would enable referring agencies to send referrals by e-mail. It would then be possible to confirm receipt of a referral via an automated e-mail. It would also improve the audit trail and reduce Millbrook's administrative burden. It is important that referring agencies receive an acknowledgement of a referral and a response to a referral. (Focus group 2)**

Millbrook needs to manage client expectations better. Set goals, and point to these goals during every single conversation with service users and referrers. Detail a plan of action with timelines and be upfront about what happens if plans change. Introduce clients to the Millbrook people who will be working on their account so they can put a name/face to the person. Be transparent about what they can accomplish and communicate regularly to provide updates.

Similarly, both the referral process and assessments could be accelerated and improved if the detailed reports (often provided by therapists) could be attached electronically to the service user's record.

- **Referrals and assessments could be sped up and improved if the detailed reports often provided by therapists can be attached electronically to the service user's record. (Focus group 2)**

Nonetheless, it would really help, say respondents, if Millbrook could proactively take steps to inform therapists when they cannot process a referral because it is incomplete or incorrect. Presently this does not happen and therapists often only learn about problems and delays with their referrals when they contact Millbrook to chase it up.



- **Upon receipt of a referral check the form and inform the therapist immediately if it is incomplete or incorrect. Therapists only learn about problems with their referrals if they chase the referral. It would help if Millbrook could tell therapists when they cannot process a referral because it is incomplete or incorrect. (Focus group 2)**
- **Let therapists know as soon as possible if a service user doesn't meet the criteria. (Focus group 2)**

In this regard, respondents suggest Millbrook utilise their own CRM systems better to manage the referral process and particularly to track equipment.

- **Use 'Millfow' (a CRM used by Millbrook), which was described as 'transparent' for the wheelchair service. It is used by external agencies to track equipment but the wheelchair button is greyed out. (Focus group 2)**

Respondents offer other solutions to Millbrook's perceived administrative problems including utilising the skills and experiences of NHS staff to provide networking, training and shadowing opportunities for Millbrook staff.

- **Utilise the skills and experience of Solent NHS Trust staff to provide training and shadowing opportunities for Millbrook staff. (Focus group 2)**
- **Set up a 'professional' network, a network of therapists**

who can support each other. (Focus group 2)

Other people suggest Millbrook be more responsive generally as this would result in a more efficient, dynamic and open culture.

- **Respond in a timely fashion - this would result in more efficient system as less time would be spent chasing responses and updates. (Focus group 1)**

As high quality wheelchair services are a vital key to the independence of disabled people of all ages, it is imperative that Millbrook address the suitability of wheelchairs issued. The patient's lifestyle, functional needs, postural control, medical condition and tissue viability have to be taken into account in developing the most appropriate solution. It is essential that all wheelchair options are explored and discussed with all concerned so that the most suitable wheelchair for the individual service user can be determined and the all too familiar stories of delivered chairs not always meeting the specifications from the assessments, leading to further delays and unmet needs leading to psychological and physical discomfort for service users. The function, appearance and operation of the equipment needs to be explained to the patient, if possible, and other relevant persons before the equipment and specification is finalised.

As part of the handover process the client or authorised carer should be advised how to obtain repair & maintenance for the equipment. This should include details of on ongoing support from the wheelchair service with named contacts and correspondence details provided. This has not always been the case but providing a patient-focused service that is based on the individual needs of the wheelchair user needs to be an integral part of the Millbrook service going forward.

Another suggestion to improve the service would be to provide opportunities for Millbrook staff to meet service users to understand their predicaments. Similarly, providing both disability awareness training and wheelchair familiarisation training to all call centre staff is also seen as useful step forwards in improving service levels.





- **Provide opportunities for staff to meet service users and provide both disability awareness training and wheelchair familiarisation training to all call centre staff. (Focus group 1)**

Other suggestions include Millbrook actively testing new and also repaired chairs before they are (re)issued as this could help to improve service efficiencies.

- **Test chairs fully before leaving after a repair has been completed. (Focus group 1)**
- **Chairs need to be tested by an engineer immediately prior to issue. (Focus group 1)**

One recommendation suggested by focus group participants to improve the efficiency of the repair service was the provision of a dedicated email address that service users could use for repairs. This was seen to help provide both an audit trail and if photos could be attached, it would also provide further evidence of the part that needed to be repaired or replaced. This might help to accelerate repairs as engineers would then be able to visibly ensure that they had the correct part on their vans ahead of a call out.

- **Provide an e-mail address that service users could use for repairs. (Focus group 1)**
- **Use e-mail as they could then have an audit trail and they could also attach a photo of the part that needed to be repaired or replaced. This might speed up repairs as engineers would be able to ensure that they had the correct part on their van. (Focus group 1)**
- **Provide users with a labelled photo or diagram of their chair indicating the main parts, which they can use when they phone up about a repair. (Focus group 2)**

Other suggestions for the improvement of the service include the provision of an inventory / checklist when a chair is issued and for each chair to have a unique number which can be linked to a service user.

- **Provide an inventory/checklist of equipment when a chair is issued. (Focus group 1)**

Millbrook need to be more responsive generally as this would result in a more efficient, dynamic

and open culture. Millbrook needs to keep customers better informed, more often. Millbrook could let people know in advance how often they will be in contact and during which times and channels it is most convenient to be in touch. Any changes with the scheduling of deliveries, assessments, referrals, repairs, equipment etc. should be noted to the client in a timely manner.

Office staff need to have a much better knowledge of their products and services. They should also consider employing more disabled workers in the office as many of them have experience of living with adaptive technologies, and understand from a user perspective, how to answer challenges in the most appropriate and respectful manner.

There was a tangible perception around both focus groups that the wheelchair contract has become so large the service has become unmanageable and impersonal; having some knowledge of each service user therefore could help to remedy the faults in the provision and improve customer service levels.

- **Service users get worried when it appears that Millbrook don't know what equipment they have. It might help to have a unique number on each chair. Having some knowledge of service user improves the service. As the contract is so big the service has become impersonal. (Focus group 2)**

- **Improve record keeping - Call centre staff should be able to see what the last contact with the service user was for and should be able to see what chair or chairs the service user is currently using. (Focus group 2)**





Other proposals for service improvement include the provision of quick triage for priority cases

- **Provide a quick triage for priority cases. (Focus group 2)**
- **The presenting issue needs to be used to prioritise need. (Focus group 2)**

Other respondents suggested 'Place in queue' information would be useful when someone is waiting for a call to be answered.

- **'Place in queue' information would be useful when someone is waiting for a call to be answered. (Focus group 1)**

A list of preferred suppliers might be a useful resource for those who wish to purchase their own chairs was another proposal.

- **A list of preferred suppliers might be a good idea for those who wish to purchase their own chairs. (Focus group 2)**

Other proposals include implementing a robust engagement strategy by creating improved opportunities for service users to provide regular feedback on the service

- **Create better opportunities for service users to provide feedback for example service user groups, implement the engagement strategy and involve service users in staff training as they are the experts by experience. (Focus group 1)**

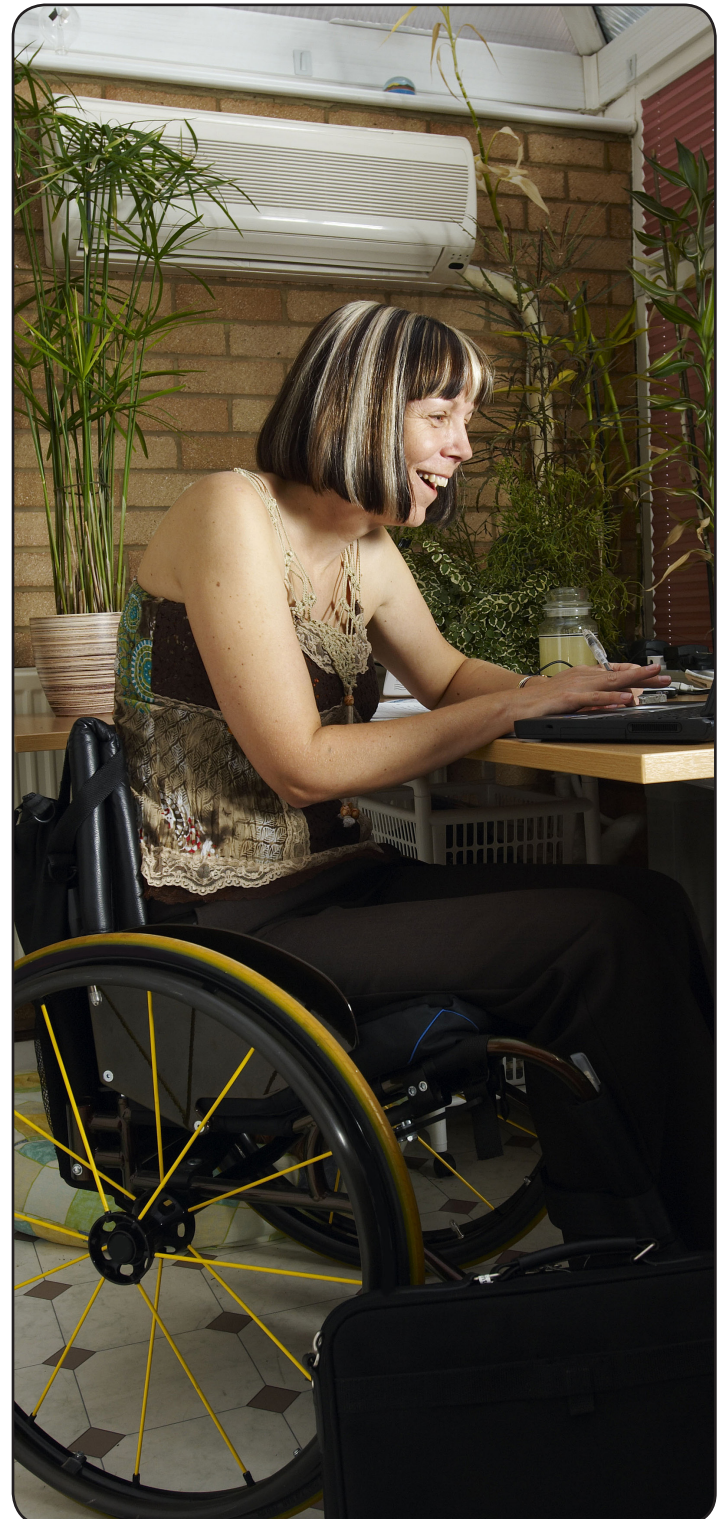
Ensuring that managers have the right experience and training to accomplish their duties and to take better responsibility for the service as whole is another proposal to improve the service.

- **Ensure that managers have the right experience and training to accomplish (Focus group 1)**
- **Millbrook to take on responsibility for 'like for like' replacements. (Focus group 2)**

This includes being able to honestly manage people's expectations by more widely sharing eligibility criteria and being more realistic and more honest with people. There was general acceptance amongst both focus groups that promises were regularly made and subsequently

broken, with little in the way of apology and/or explanation.

- **Be honest and realistic with service users and therapists. 'Don't promise to do something if you have no intention of doing it' for example 'I'll call you back' and don't over promise. (Focus group 2)**
- **If you can't do it, don't say you can. (Focus group 1)**





What Next?

This report represents part of the full service review of Millbrook Healthcare carried out by West Hampshire CCG. The full review evaluated the operation of the process by which people referred into the service are assessed and receive their wheelchairs, the repair service, all quality aspects of service delivery, demand and capacity, investigation and handling of complaints, and communication processes.

This report has been shared with West Hampshire CCG and used to inform the overall recommendations in the final review. The scope of the service and context in which it operates are set out in the full report of the service review which is available here www.westhampshireccg.nhs.uk.

This report and a full copy of the service review will be available on the Healthwatch Hampshire website.



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