

# How do we make Wirral a better place to live for people with a learning disability and their families?

## Wirral Mencap Consultation Report

[www.mencapwirral.org.uk](http://www.mencapwirral.org.uk)

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## Executive Summary

Wirral Mencap has gathered data from over 160 people with a learning disability and/ or family carers to establish the main concerns and aspirations of people living in Wirral. The data includes information gathered via surveys, focus groups, accessible consultation exercises and statistical information from existing service provision.

The data has been analysed and themes have emerged. The report highlights the prevalence of the following viewpoints:

- Concern about the future and the sustainability of current housing/ support arrangements (whether at home with aging carers or in supported living/ residential)
- Financial concerns including difficulty accessing entitlements and employment (for family carers and people with a learning disability)
- Concerns regarding weight, diet and fitness
- Inconsistent application of specific health initiatives such as the Health Passport Scheme
- Difficulties accessing preventative health services and lack of specialist knowledge amongst medical staff
- Good range of social and leisure opportunities delivered by the community sector but gaps during holiday times and in relation to more 'active' pastimes
- A strong desire to learn new skills amongst people with a learning disability but a lack of opportunities to 'maximise independence' and 'reach potential'
- Experiences of 'patchy' and 'shrinking' services contributing to feelings of dissatisfaction and feeling 'unsupported', amongst carers.

The data also includes positive experiences and viewpoints, and many suggestions for how services and personal circumstances could be improved, both of which have contributed to the following recommendations:

- Better forward planning for parents/ carers/ families including access to information and services *before* crisis
- Better 'matching' in supported living (people, place and provider)
- Greater exploration of 'shared ownership' opportunities
- Support for families in accessing the correct benefits and entitlements
- Greater employment support and opportunities for people with a learning disability *and* family carers (particularly where financial dependency is occurring)
- More personal development opportunities for people with a learning disability to maximise independence and potential (including travel training)
- Access to volunteering for every person with a learning disability that would like it
- More activities for adults during the daytime and holiday times (particularly for the over 25s)
- More opportunities for health education and physical activity (including things like sport, swimming and horse riding)
- Review of the Health Passport Scheme (including the training received by health professionals)
- Exploration of more targeted delivery of preventative health services.

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## 1. Introduction

Mission Statement: Wirral Mencap exists to provide services and opportunities that improve the quality of life of people with a learning disability and their families and which create a more accessible, inclusive and supportive community.

Wirral Mencap undertook its first detailed consultation during 2012/13 to establish the key concerns and needs of local people with a learning disability and their families. The findings from the consultation informed Wirral Mencap's first 3-year strategy for the period October 2013 to September 2016.

This strategy is now being reviewed; Wirral Mencap has conducted another consultation to establish whether needs and priorities have changed. The findings from this consultation will help shape the organisation's next 3-year strategy (2016-2019).

The consultation is also intended to inform wider policy making and strategic development in Wirral, within the Public, Private and Third Sectors. This report (along with the raw data) will be shared with partners from Health, the Local Authority, Education and Community Organisations.

## 2. Methodology

### 2.1 Data Collection

**Parent/ Carer Survey:** A parent/ carer survey was designed in consultation with Wirral's Learning Disability Self Assessment Framework Group (See Appendix A for member organisations). The survey included questions relating to Health, Housing, Personal Development, Leisure and Support for Carers (see Appendix B). The survey was distributed to approximately 300 family carers via Wirral Mencap's membership, existing users of Wirral Mencap's services, social media and via members of the LD SAF. 59 responses were received.

**Members' Focus Group:** Wirral Mencap organised a focus group for members of the organisation with a learning disability, centred on the topics covered in the parent/carer survey. 7 people attended and participated in the focus group (see Appendix C for transcript).

**Accessible Consultation Exercise:** Wirral Mencap designed an accessible consultation exercise to gather data regarding the broader concerns and aspirations of local people with a learning disability. This involved asking two key questions with multiple choice answers (pictorial format): "What worries you?" and "What would you like to do in the future?". The exercise was conducted at a number of venues throughout December and January 15/16, including; Wirral Mencap's Christmas Open Day, Wirral Mencap's Gateway Award sessions, The Crossbow Social Club at Charing Cross Methodist Centre and Cambridge Road Day Centre. 51 people with a learning disability participated in total.

### 2.2 Limitations

The data set had a number of significant limitations:

- Age of participants– Vast majority were *adults* with a learning disability and/or their carers
- Level of engagement with services – The majority of respondents were well engaged with services (voluntary sector and/ or statutory) disproportionately representing the views of those already in receipt of some support/ services.

### 2.3 Mitigating action

To counter the effects of the limitations outlined above we have included data from Wirral Mencap's Outreach service which provides information, advice and support to any person with a learning disability and/ or their family carers (no age restrictions or eligibility criteria apply). The service was developed to provide practical support to individuals and families in navigating services, accessing support and entitlements and avoiding crisis situations. Users of the service include those accessing little/no support from other agencies/ statutory bodies and younger families.

Case files for people accessing the service between 1 January and 30 June 2016 have been analysed and information included regarding the key concerns of these individuals/ families and their presenting issues.



### 3. Demographics and other key statistics

#### 3.1 Parent/ Carer Survey

Total responses = 59

Age range of family carers = 46 to 89 (mean = 65.6)

Age range of persons' cared for = 10 to 70 (mean = 38)

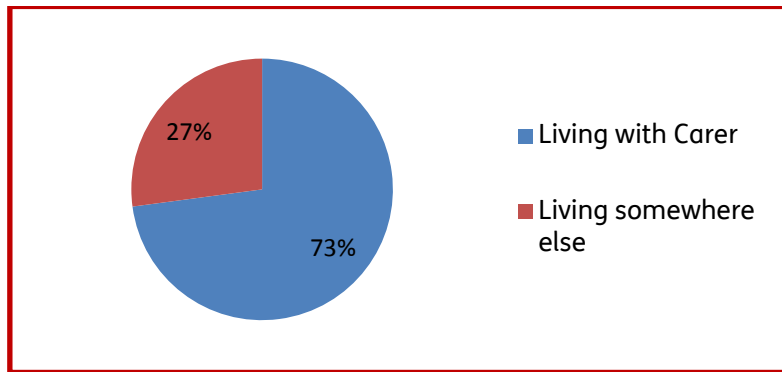


Figure 1 : Living Arrangements

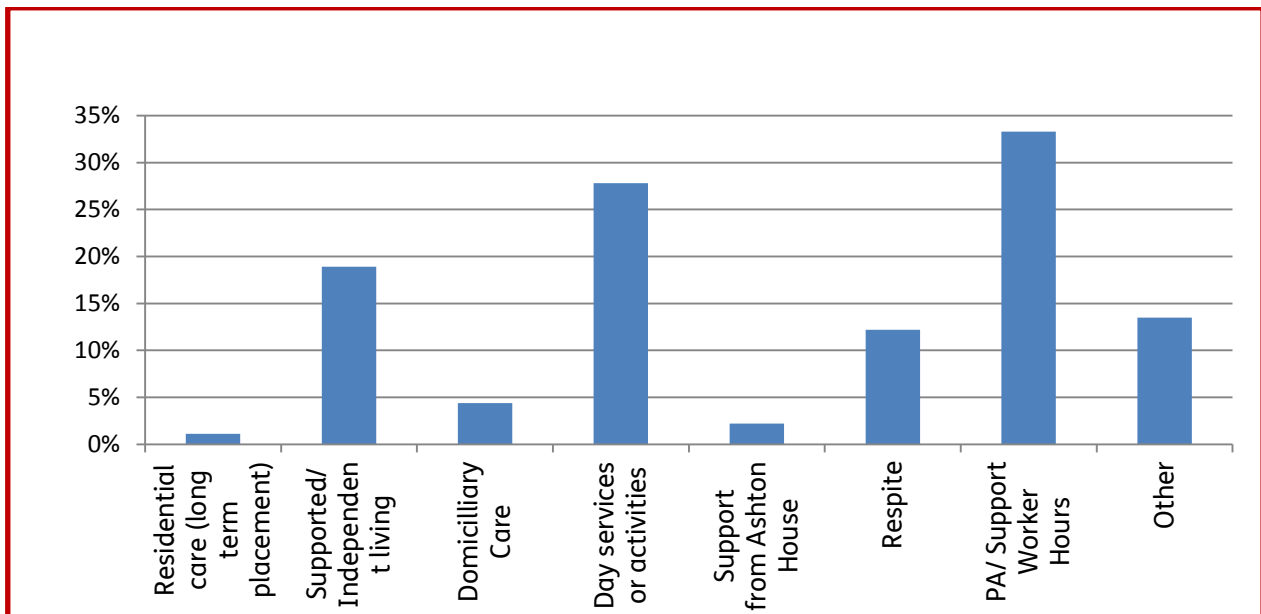


Figure 2: What services are they currently accessing?

#### 3.2 Members Focus Group (with adults with a learning disability)

Total participants = 7

Age range = 19 to 53 (Mean = 31)

### 3.3 Accessible Consultation Exercise (with adults with a learning disability)

Total Participants = 51

Age range = 18 to 66 (Mean Age = 42)

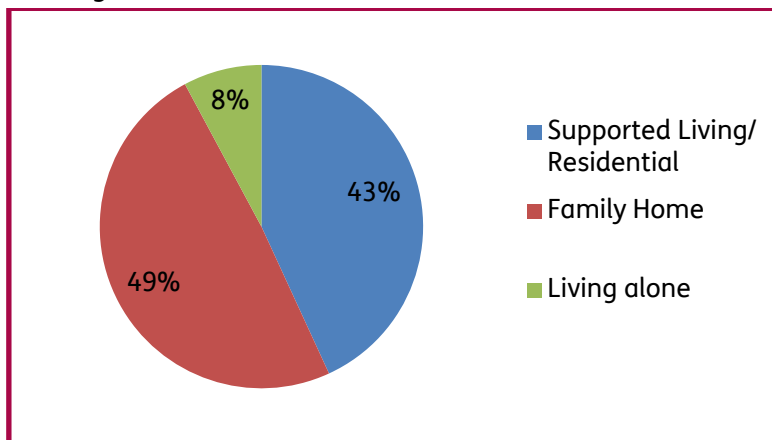


Figure 3: Living Arrangements

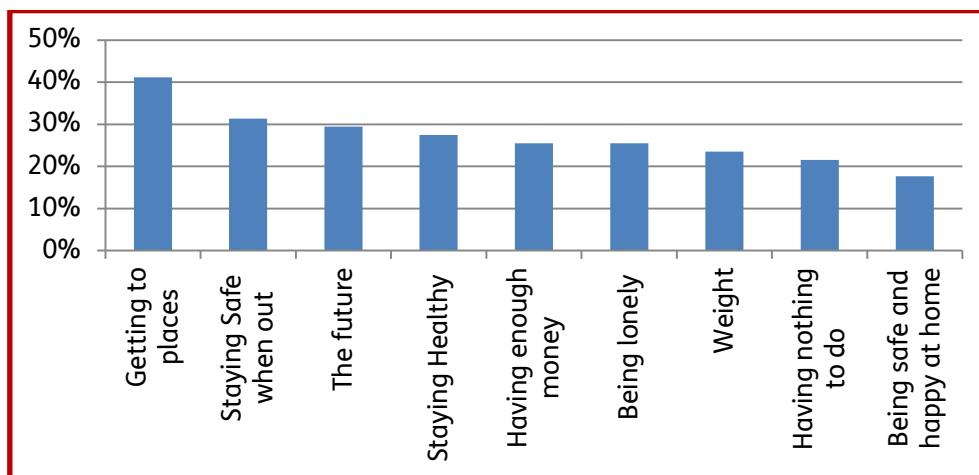


Figure 4: Responses to 'What worries you?'

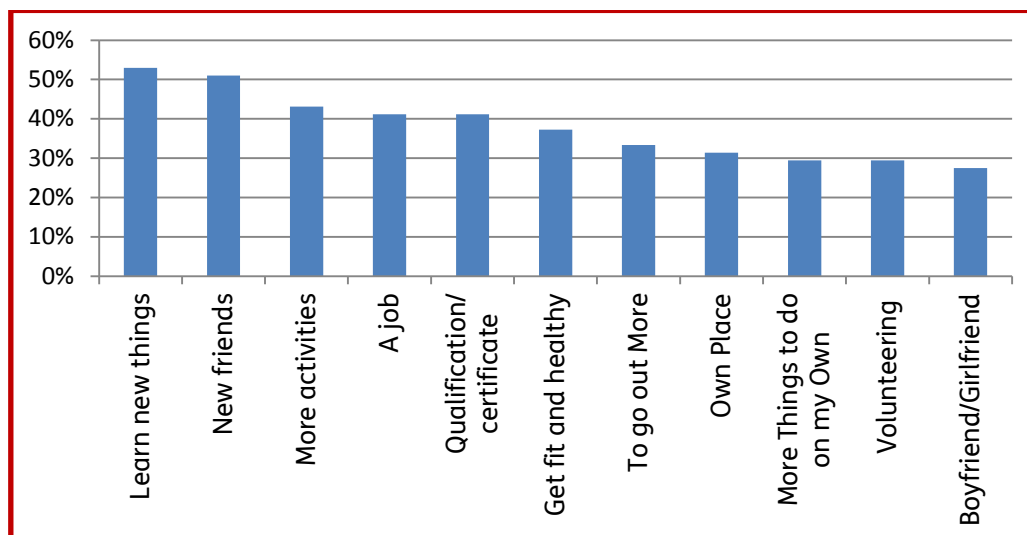


Figure 5: Responses to 'What would you like in future?'

### 3.4 Outreach Case Files

Total Cases (between 1 January and 30 June 2016) = 56

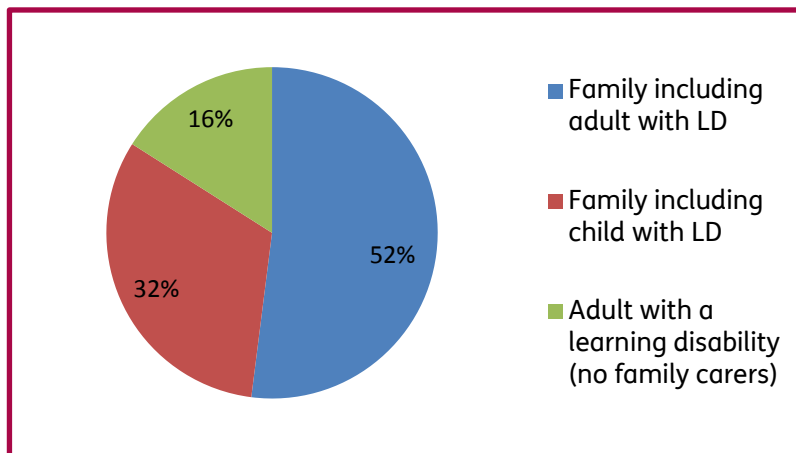


Figure 6: Case Type

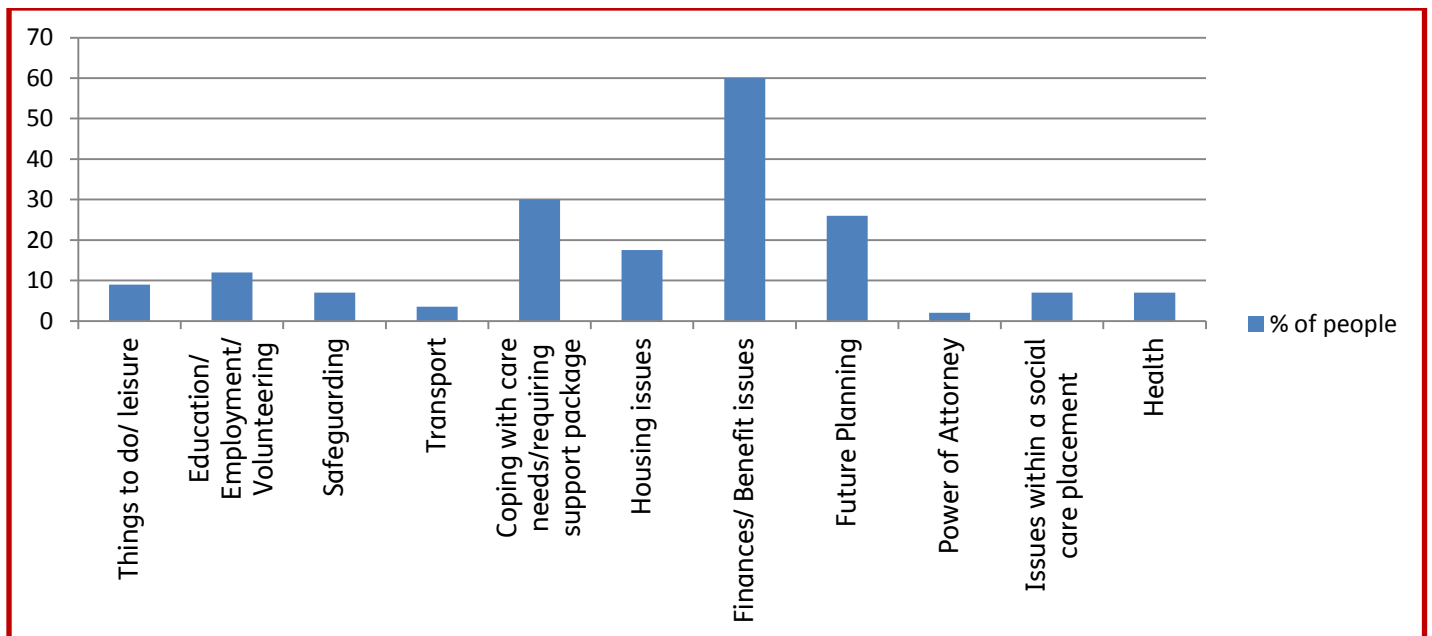


Figure 7: Presenting issues/ concerns



## 4. Key Findings

### 4.1 Housing, Support and Future Planning

Themes emerged from the parent/ carer survey data in relation to housing and support. Where parents/carers felt arrangements were working well, the data suggested that there were two common scenarios:

(1) They were caring for someone in the family home and were in good health, with good support networks and access to home adaptations where necessary:

***“He lives at home with both parents in a pleasant environment with siblings just a few miles away”***

***“..... she lives with us and we have adapted our home to meet her needs”***

***“We totally care for her. Food, accommodation, health, financial and social needs”***

***“I am young enough to look after him and he is happy here with all his home comforts - own room, tv, computer”***

(2) The person they care for was now living in an establishment suited to their needs, with good support, a good mix of people and in a good location:

***“The place where our daughter is supported is a new build and is perfect for people like her, there are other young adults all with their own flats and 24/7 care”***

***“She lives in a small 3 bed bungalow with 1 friend. It feels like a home not institution. It is in a nice area. And neighbours are friendly.”***

***“Well laid out mini housing complex. Lovely established area. 1 mile away from parents home. Housing near facilities, station, buses, trains, shopping, cinema”***

From the responses received, it would appear that the majority of family carers fitted into one of the scenarios outlined above; as a consequence, they stated that housing and support arrangements were suitable *at present*.

Data from the Outreach case files told a slightly different story. Individuals/ families that accessed the service frequently presented with issues relating to housing or support; 30% of cases between January and June 2016 related to families struggling to cope with care/ support needs at home; and 18% related to housing issues. As discussed in the limitations (section 3.2), the Outreach service works with a broader range of people, including those who have less access to/ engagement with services.

Regardless of whether family carers felt housing/ support was suitable at present, there appeared to be widespread concern regarding the future. Two-thirds of family carers in the survey expressed concerns about future housing and support arrangements. For those currently caring at home, the concerns generally related to age and a lack of natural support networks:

***“At the moment I am able to look after my son. I’m coming up to 80 years next year and I’ll have to look for residential for him, if I’m unable to look after him”***

***“Beginning to question his future on account of my age and current lack of accessible support - old neighbours have left and friends no longer in a position to help”***

As well as concerns about their own age and capacity to continue caring, family carers also expressed concerns about the suitability, safety and availability of social care provision. In their responses, many recognised that they could not continue indefinitely, but they raised concerns about the alternative options:

***“lack of suitable housing options, austerity and cutbacks, poorly paid carers, evidence of abuses towards people with Id such as winterbourne view. We are getting older.....”***

***“Providing the right property in the right area and environment. Getting the right group/ mix of people together with appropriate support and sustaining it”***

***“do not believe there is suitable housing for him..... he will probably require 1/1 support which I'm unsure is available on Wirral”***

Even families that stated they were happy with existing provision had concerns about sustainability:

***“I am delighted with the placement at the moment but worry that, as the house is shared, if the person she is sharing with should move out, who she would be paired with and how the bills etc would be handled. It is a great concern.”***

***“Will always be concerned about any future changes to any government policies, which may affect or reduce the support they receive, or to the security of their home tenancies being threatened at a later date.”***

Fears over the ‘future’ were also apparent amongst people with a learning disability. Almost a third of participants in the accessible consultation exercise stated that they were worried about the future (see figure 4), making it the third most commonly selected concern.

Parents/ carers that expressed a greater sense of security frequently mentioned things like; good family support networks, planning ahead, good housing associations and/or shared ownership schemes:

***“We have a plan in place and family members”***

***“Secure future, fingers crossed, as shared ownership with excellent Housing Association”***

***“with good agency.....in good area”***

***“as they are in a bungalow no problems as they get older and they own 1/3 each”***

Data from the Accessible Consultation Exercise and Focus Group highlighted that some people with a learning disability aspire to living more independently; in the accessible consultation exercise, just over a third currently living in their family home stated that they wanted their own place. In addition, ‘moving out’ was a common theme in the focus group; 3 of the 7 participants spoke of wanting their own place in the near future.

## 4.2 Money matters

Money worries were common amongst individuals and families that participated in the consultation. 48% of family carers that responded to the parent/ carer survey stated that they had financial concerns. Many made reference to low incomes and rising costs of living:

***“Utilities and food prices are very high and benefits low. I worry about him having a good quality of life if it gets any worse”***

***“We hardly have any extra money to live on and the bills seem to be getting higher”***

Some people with a learning disability also expressed financial worries; a quarter of people that participated in the accessible consultation exercise selected ‘having enough money’ as a concern.

The prevalence of financial concerns was also highlighted by the Outreach data; ‘finance and benefits’ were the most common reasons for people accessing the service between January and June 2016, with 60% presenting these types of issues. Many of the individuals/ families required information or practical support in order to access the correct entitlements, including support to complete paperwork or appeal decisions.

Employment inequalities were apparent amongst people with a learning disability and family carers. In relation to people with a learning disability, only two of the 59 respondents to the parent/carer survey stated that the person they cared for had a paid job, and just one of the participants in the members’ focus group referred to a paid job. However, 41 % of people in the accessible consultation exercise aspired to having a job in future.

A majority of carers stated that they were also unemployed (although many were at retirement age). Those that were of working age frequently mentioned caring responsibilities as the reason why they were unable to access employment opportunities:

***“Not enough free time to work, my days can be 16/17 hour days, up early, he refuses to go to bed at times”***

***“My sister needs 24 hour care”***

***“Too many hospital/ GP appointments etc. Need to be home for daughter as she has epilepsy. Can’t find a job that would fit the hours I can do”***

***“As I am unable to return to full time work, we will have to sell our home in the near future and look to go into rented. I am also concerned that I will only have a state pension and that once my son leaves school I will be worse off as I will be even more restricted to work availability.”***

In some cases, family carers made reference to the financial dependency that had arisen due to their limited employment opportunities and the difficulties they would face in re-entering the workforce should the person they care for leave home with their associated benefits:

***“If he was in full time care I would probably have to move from my home”***

***“Do worry about my financial situation after my sister has either had to go into full time care or passed away..... I am at an age where I might find it hard to get back into work.”***

***“Worry about how I will cope in the future especially when my daughter leaves home and I am too old or worn out to get a job***

### 4.3 Health

Many parents/ carers expressed concerns regarding the health of the person they care for. Weight, diet and fitness were the most common concerns with 40% of parents/ carers referring to these areas.

When asked how health of people with a learning disability could be improved, many family carers made reference to more physical/ health related activity in Day Centres and better access to community provision:

***“More exercise at Day Centres”***

***“By a daily walk, weather permitting, around the Puddydale for clients at Heswall Centre”***

***“To be encouraged with support to attend council run recreation centre fitness suites and swimming.”***

***“Involving them in community activities and give them same opportunities as those without a disability as a part of their support plans.”***

Many family carers also referred to general health and the NHS. Many parents/ carers felt that health would be improved if services were more specialised or if clinical staff had more specialist training:

***“Having clinics specific to address the issues that people with learning disabilities have e.g fear of needles, quiet environment etc”***

***“.....I think all surgerys should have a particular doctor/ nurse who has been trained in care for people with disabilities”***

***“More training to staff doctors etc. Listen to parents and communicate more with parents...”***

There were also references to access, and suggestions that targeted services in Day Centres and other venues could improve health:

***“Maybe dentist/ chiropodist/ eye tests could be available in centres to those with elderly parents and people with disabilities who are afraid of going to places”***

***“Flu vaccinations given annually at day centre”***

The survey also asked family carers about two health initiatives that had been designed to help reduce health inequalities for people with a learning disability; Annual Health Checks, and Health Passports (a document containing information about a patients’ needs to be taken to appointments/ when admitted to hospital). In the main, experiences of Annual Health Checks were positive, and awareness of the service was good with 81% of carers stating that the person they care for had been offered one (which a high majority had attended):

***“Yes we attended a positive experience where necessary health monitoring can be organised and any health concerns addressed”***

***“Very considerate and informative. Referred to "live well" clinic”***

Where experiences of Health Checks were less positive, there were often references to training:

***“Disappointing but surgery has since taken advantage of some training I believe”***

***“We attended, I was in the room with her and the nurse directed the questions at me by replying for our daughter e.g. "you don't have a boyfriend do you?" and "you don't smoke, do you?". Good to be asked, but lots of training in LD required.”***

Experiences of the Health Passport were more varied. In the survey, 52% of family carers stated that the person they care for had a health passport; many felt they were a good idea but they weren't given enough attention by health professionals:

***“Does the system work? Does not appear to be used by hospitals/ doctors etc”***

***“It's a very good idea..... however we have found not all hospital staff read it”***

***“Very useful. All depends if it is read properly by attending medical staff!”***

***“Waste of time, nobody ever asks for it and when asked people do not seem to know about it”***

Health was also important to some people with a learning disability that participated in the consultation; 27% of people in the accessible consultation exercise selected 'staying healthy' as a concern, and 37% selected 'get fit and healthy' as an aspiration.

Participants in the focus group also considered health as part of their discussion. The majority expressed good understanding in regards to how they could stay healthy with many making references to exercise or sport such as walking, basketball, football and Wii Fit. There were also some references to diet such as cutting down portion sizes and reducing sugar intake.

In regards to improving health, one participant suggested setting more health challenges/ targets as part of activities like the Gateway Award programme (Wirral Mencap). The majority of participants (5 of 7) also stated that they would be interested in joining a fitness club or specific activities like walking and swimming groups.



## 4.4 Personal Development and Aspirations

A majority of family carers felt there were opportunities for the person they care for to develop new and existing skills, but over half felt that they still weren't reaching their full potential. Many family carers made reference to a need for more courses, intensive learning opportunities and more opportunities that stretch/ push people to achieve more:

***“Just keeping on pushing them - still too much sitting around”***

***“Repetition - time is not always freely available to spend on one student”***

***“One to one repetitive instruction very time consuming and expensive it will never happen”***

***“M loves IT but tends to find all the present courses cover the same things. He would like to learn new things.”***

***“Now that she is 18 and has just left college, it would be good to be involved in planning her future as we know her best and know exactly how she could be "stretched" rather than being on 1:1 at all times”***

People with a learning disability also expressed a desire for personal development. In the accessible consultation exercise, ‘learn new things’ was the most frequently selected aspiration, even more popular than ‘new friends’ and ‘more activities’ (which were the most popular choices 3 years ago). ‘Getting qualifications/ and or certificates’ was also selected by over 40%.

Focus group members also discussed personal development/ learning opportunities. Two participants spoke of accessing courses, with one informing the group that they had achieved a qualification. A majority of participants (5 of 7) stated that they were currently engaged in some form of volunteering with one also having a paid job. Those that didn't have a volunteering placement or job stated that they would like one.

In regards to learning opportunities, one participant in the focus group suggested that travel training may help more people become independent. Issues relating to travel were highlighted in the accessible consultation exercise with participants selecting ‘Getting to places’ and ‘Staying safe when out’ as their two greatest concerns (selected by 41% and 31% of people respectively).

## 4.5 Leisure and socialising

The general consensus amongst family carers in the parent/ carer survey was that there *are* opportunities for people with a learning disability to ‘access meaningful activities’ and ‘make new friends’ in Wirral (96% and 85% selected yes to these questions respectively). However, as discussed in the limitations, the majority of responses came from those already well engaged with services. These parents/ carers frequently mentioned the same types of activities and venues i.e. day centres, evening social clubs and church groups. They also mentioned going out with carers (paid or unpaid).

***“He attends several clubs a week e.g. Orion Club run by Heswall Methodist Church. His carers take him out regularly evenings and weekends. He also goes on holiday a couple of times a year”***

***“He regularly attends outings with his church also attends Crossbow Club”***

***“Attends evening activities twice a week and carer once a week to take part in leisure activities”***

***“She attends a day centre four days a week and dale farm on the other day. Has a club every Monday (orion) and once a month club at St Lukes Hoylake. Weekends I take her out”***

***“Attends Sherlocks, St Marys Club, Hot Wheels at night with support workers. College and Best Bites Bistro in the day”***

***“Does good activities at Oakenholt. Attends Crossbow Club and other activities and events.”***

A number of parents/ carers also referenced ‘Volunteering’ in regards to leisure:

***“He volunteers at a charity shop and attends 2 evening clubs.”***

***“He does his volunteer work.....and goes to several clubs in the evening.”***

When asked whether there were gaps in leisure provision, many family carers made reference to holidays or specific activities such as swimming, horse riding and sport:

***“Used to really enjoy the sports and leisure activities provided by sports development however they have largely ceased due to funding cuts”***

***“He loves swimming but I cannot find anyone to take him. It would be valuable exercise”***

***“Holiday clubs”***

There were also references to ‘dwindling’ opportunities once people reach their mid twenties:

***“There is a big gap in services once they reach 25”***

***“What is available past 24 that doesn't cost the earth?”***

***“Provision seems to be overlooking those over school age.”***

The views of parents and carers were mirrored somewhat by people with a learning disability in the focus group. Focus group members spoke of having 'enough [evening] clubs' but mentioned specific gaps such as holiday times.

For those not eligible or accessing daytime provision, there was also some interest in drop-in daytime activities such as art groups.

The accessible consultation exercise highlighted a desire for more leisure and social opportunities amongst people with a learning disability, with 43% selecting 'more activities' and 51% 'more friends' as aspirations for the future.

## 4.6 Support for carers

In the parent/ carer survey, 55% of family carers stated that they did not feel well supported in their caring role. Some made reference to difficulties getting a social worker, accessing services and/or a lack of natural support networks:

***“impossible to get social worker unless in crisis”***

***“Single carer”***

***“Have been told that I should get respite over winter holidays but still being decided by joint panels”***

There were also references to dual/ additional caring responsibilities:

***“Enjoy respite care but cannot get away on holiday at the moment as I care for my husband who has Parkinson’s disease”***

***“My lifestyle includes looking after my son and helping my mum with various activities”***

***“I am dual carer, also care for elderly parent so chasing tail constantly. Respite dates are preset and not of our choosing”***

In contrast, those that felt well supported referenced links with charities, good support agencies/ PAs, Day Centres and family/friends.

***“Other parents in similar situations, Mencap, DS@Wirral”***

***“Havencare and a PA. Also my partner”***

***“My family visit from time to time and there is the Centre for P, most essential!!”***

***“My sister lives in independent living and we are very happy with staff and links we have with them”***

***“Family and friends”***

Almost two-thirds of family carers who responded to the survey said they get a break from their caring role with a majority mentioning either specific respite services, day centres, church activities or community groups:

***“He attends day centre, 3 times a week. Goes away for weekends with Church. Goes on annual weeks holiday with Crossbow Club”***

***“We are currently offered 6 weeks respite a year which we rely on so that we get a complete break”***

***“We get 6 weeks a year and access to day centre 3 times per week”***

In contrast, almost a fifth stated that they had not been offered a break from their caring role at all:

***“I had my daughter at home until 01/08/15, I was never offered any sort of respite”***

Overall, family carers rated their satisfaction with services and support in Wirral as 5.4/10. In regards to the quality of services, there were many references to shrinking services, 'patchy services' and difficulty navigating services:

***“Generally the support is good, but services seem to be shrinking across the board”***

***“There has been too many cuts to services/ staff. Trying to contact social services is almost impossible.”***

***“There is too much form filling, red tape, too many organisations/ dept don't always know where to go to get help.”***

***“My son appears to be totally off all records of help and education in the Wirral. All his day centres, voluntary jobs etc have been closed. No options for anything else”***

***“Access to information and advice is poor which means that many people are totally unaware of what is available, hence score of 2. However there are good services available should you be lucky enough to hear about them, then climb any hurdles to access”***

***“Support in social services are patchy and difficult to access”***

## 5. Conclusions

The future remains a major concern for people with a learning disability and family carers. This consultation highlights the prevalence of worries relating to future housing, support arrangements and finances. The individuals and families that participated in this consultation frequently referenced issues such as the age and health of carers; availability, suitability and sustainability of housing/support provision; and the potential for future cuts to budgets, services and benefits.

The responses did include some positive outlooks and these cases highlight the positive impact of things like: forward planning; natural support networks; effective 'matching' of people, location and support providers in supported living; and schemes like 'shared ownership'.

The demographic information also highlights that individuals/ families require support at different times in their lives. Some family carers feel able to continue caring later in life but this can sometimes result in them having multiple caring responsibilities as parents/ spouses age. Similarly, they can find their own health deteriorating – For these families, having a plan in place, good family/ friends and/ or access to a social worker *before* crisis can help them to feel more secure about the future. The importance of regular breaks for those caring at home was also highlighted by the consultation and in the most part carers stated that they *were* getting breaks if desired. However, less than half stated that they felt well supported as a carer and on average carers rated their satisfaction with services in Wirral as 5.4 out of 10. Difficulties getting hold of a social worker and shrinking/ patchy/ inaccessible services appeared to contribute to the poorer satisfaction ratings. Those that did feel well supported regularly mentioned charities/ community groups, good supported living staff/ PAs, day centres and family/friends.

The prevalence of financial concerns was also apparent (in relation to present circumstances as well as the future). The Outreach data suggests that information and support is often required to ensure families have access to the correct benefits and entitlements. A further issue identified by the consultation is the financial dependency that some carers are facing due to limited employment opportunities (not only whilst caring but after their caring role ends due to limited chances to gain skills and experience necessary to re-enter the job market after a long period of unemployment).

In regards to health, the consultation established that weight was the greatest concern amongst the family carers that participated (as well as being a concern of around 25% of people with a learning disability). Many people felt this could be improved through increased opportunities for physical activity (either at Day Centres or mainstream provision). People with a learning disability also expressed interest in more fitness-related clubs and activities.

In regards to specific health initiatives, there appeared to be good awareness and take-up of Annual Health Checks, and experiences in the most part were positive. Feedback on Health Passports, however, was mixed. Many people agreed that they were a good idea but outlined scenarios or experiences that suggested that they were not always working in practice. Family carers felt that general health could be improved by more specialist services, staff training and the targeted delivery of services where people regularly were (e.g. day centres).

In the most part, family carers and people with a learning disability felt that there *were* opportunities for leisure and socialising, but they tended to refer to the same types of activities, which may not be available or accessible to all (i.e. day centres, church activities and evening social clubs). The data from



the various exercises suggested that there were gaps, including: activities for the over 25s; specific activities like sport, horse riding and swimming; and activities during holiday times.

Responses relating to personal development and learning opportunities were varied. Just over half the family carers in the parent/ carer survey felt that the person they cared for was *not* meeting their full potential. Many felt that more courses, intensive learning opportunities and services that ‘push’ people with a learning disability would help. The *desire to learn* was evident amongst people with a learning disability in both the focus group and accessible consultation data. Participants in the focus group spoke of courses they were accessing and ‘Learning something new’ was the most commonly selected aspiration in the accessible consultation exercise (with over 50% of participants selecting it). The importance of volunteering was also highlighted in both the focus group discussion and consultation data. The lack of people with a learning disability in paid employment was evident throughout but the accessible consultation data highlighted that it was a common aspiration (selected by 41% of people).

‘Getting to places’ and ‘staying safe when out’ were the two greatest concerns of people with a learning disability that participated in the accessible consultation exercise. Independent travel was also a key theme in the focus group discussion.

## 6. Recommendations

In order to 'Make Wirral a better place to live for people with a learning disability and their families', it would appear that progress is required in the following areas:

- Forward planning for parents/ carers/ families including access to information and services *before* crisis
- Better 'matching' in supported living (people, place and provider)
- Greater exploration of 'shared ownership' opportunities
- Support for families in accessing the correct benefits and entitlements
- Greater employment support and opportunities for people with a learning disability *and* family carers (particularly where financial dependency is occurring)
- More personal development opportunities for people with a learning disability to maximise independence and potential (including travel training)
- Access to volunteering for every person with a learning disability that would like it
- More activities for adults during the daytime and holiday times (particularly for the over 25s)
- More opportunities for health education and physical activity (including things like sport, swimming and horse riding)
- Review of the Health Passport Scheme (including the training received by health professionals)
- Exploration of more targeted delivery of preventative health services

As an organisation with limited resources it is important that we concentrate *our* efforts in areas where we can have the greatest impact. This will be explored further in our strategic plan. It is essential that we work in ways that have a lasting impact as opposed to only solving immediate problems. For example, where possible we must empower individuals and families through the support we provide so they are better able to manage issues in the future.

We must also ensure that we communicate these findings (which have come directly from people with a learning disability and their families) to other organisations and commissioners so they can inform future service design and delivery. This includes mainstream service providers if we want to make progress in creating a more inclusive Wirral.

For further information or to discuss the findings of this report, contact Chloe Harvey on 0151 666 1829 or [charvey@mencapwirral.org.uk](mailto:charvey@mencapwirral.org.uk).

## Appendix A – LD SAF Membership

- Wirral Community NHS Trust
- Wirral University Teaching Hospital NHS Foundation Trust
- Cheshire and Wirral Partnership NHS Foundation Trust
- Public Health Wirral
- Wirral Borough Council
- Wirral Mencap

## Appendix B – Parent/ Carer Survey

# How do we make Wirral a better place to live for people with a learning disability and their families?

## Questionnaire for parents and carers

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Wirral Mencap is an organisation that supports people with a learning disability and their families. We want to see improvements in the services and opportunities available in Wirral; across health and social care, education, leisure and the wider community.

You can help us strive to make Wirral a better place to live by completing this short questionnaire. It should take no more than 10 minutes.

The questionnaire asks about

- Any concerns you may have as a parent/carer
- Existing services and how they could be improved
- Anything that might be missing in Wirral

We will use your responses in two ways:

1. To help shape our own services so we are offering the right support at the right times.
2. To inform and influence service providers from health, social care, leisure and education, so they are more aware of what is needed in Wirral.

Please complete and return to:

Wirral Mencap  
42 – 44 Market Street  
Birkenhead  
CH41 5BT

### Privacy Statement

The results of this survey will be shared with partners across health, social care, education and leisure but all personal information (e.g. name, contact information) will be removed beforehand so you cannot be identified from your responses.

***Returned questionnaires will be entered into a prize draw for a £50 supermarket voucher!***

## About the person you care for

1. How old is the person(s) you care for?

2. Are they male or female?

Male  Female

3. Does the person you care for live with you?

Yes  No

4. Please provide the first four digits of their post code/ your postcode if living with you:

C  H

5. Do they receive any of these services?

Residential Care (long term placement)  Supported/Independent Living  Care in the home

Day Services or activities  Support from Ashton House  Respite

Direct Payments/ Personal Budget to pay for support

Anything else?

## Housing

1. Do you think the person you care for is in suitable housing at the moment?

Yes  No

Please tell us your reasons for selecting 'Yes' or 'No'.

2. Do you have concerns over their future housing needs?

Yes  No

Please tell us your reasons for selecting 'Yes' or 'No'.

1. Do you have any of the following concerns related to the health of the person you care for?

Weight/Diet/Fitness       Smoking       Alcohol/substance misuse

Sexual health, education and/ or relationships       Going for screening       Podiatry

Dental health      Anything else?

2. Have they been offered an annual health check from their GP?

Yes       No

If yes, did they go and what was it like?

3. Do they have a health passport?

Yes       No

If yes, what do you think of the health passport?

4. How could the health of local people with a learning disability be improved?



## Personal Development: Education, Training, Volunteering, Work

1. Does the person you care for access any of the following?

- School (Mainstream)       School (SEN)       College  
 Paid employment       Volunteering      Other informal learning/courses: \_\_\_\_\_

2. Do they have opportunities to develop new and existing skills?

- Yes       No

3. Are they reaching their full potential?

- Yes       No

4. What would help them to develop their skills and reach their full potential?

## Leisure: Day time, evening and weekend activities

1. Does the person you care for have opportunities to take part in meaningful activities during the daytime, evening and/or weekends?

- Yes       No

Please explain why you have selected 'Yes' or 'No'.

2. Do they have opportunities to meet new people/ make friends?

- Yes       No

3. Is there anything they would like to do which they can't access or which isn't available?

## Support for you as a carer

1. How old are you?  2. Your gender:  Male  Female

2. If you are caring for someone at home, do you get chance to have a break?

Yes  No, it hasn't been offered  No, I've chosen not to

If you answered yes please tell us more about the respite you get. If you've chosen not to have breaks from your caring role please tell us why.

3. Do you feel well supported as a carer?

Yes  No

If yes, who is it that provides the support? If no please tell us how support could be better.

4. Are you in paid employment?

Yes, part time  Yes, full time  No

If no, please tell us why.

5. Do you have financial concerns now or about the future?

Yes  No

If yes, please tell us about your concerns.

## Other comments

1. Overall, how satisfied are you with the services and support available in Wirral? (Please circle)

1	2	3	4	5	6	7	8	9	10
Not at all					Very Satisfied				

2. Please use the space below to add any further comments, good or bad about the quality of support and services in Wirral.

3. If you think there is a gap in services, please use this space to tell us about it.

4. Do you or your family access any services or support from Wirral Mencap?

 Yes

 No

If no please tell us why?

***END – Thank you very much for taking part in this survey***

### Privacy Statement

The results of this survey will be shared with partners across health, social care, education and leisure but the slip on the following page will be removed beforehand so you cannot be identified from your responses.

If you would still prefer us not to share your answers with other services please tick this box

## For Support and Services

To find out more about Wirral Mencap and the support available please:

- Visit [www.mencapwirral.org.uk](http://www.mencapwirral.org.uk)
- Email [info@mencapwirral.org.uk](mailto:info@mencapwirral.org.uk)
- Call 0151 666 1829

This space has been intentionally left blank

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Please fill in this slip to be entered into our prize draw for a £50 supermarket voucher

Name

Telephone number

Email address

Please tick this box if you would like to hear more about the work of Wirral Mencap and the services available.

Please tick this box if you would like to be involved in a discussion group about the issues raised in this questionnaire

## Appendix C – Focus Group Transcript

### Health

Facilitator: Why is it important that we're healthy? How can Wirral Mencap help you be healthy?

A: Good in your lungs, basketball, exercise

R: A lot of sport

M: Football

R: Lots of walking to stay healthy

K: Dance on Zumba fitness on the Wii

Facilitator: Anything else you can do to stay healthy?

A: Keep fit, gym, exercise

R: Eat Healthy

K: Cut down on sugar

Facilitator: Has anyone also thought about other things like getting teeth checked, going to the dentist?

ALL: Yes

K: Recently been to dentist

Facilitator: How can Wirral Mencap help?

A: Tell us all to be healthy

G: Set challenges as part of Gateway. We've all set ourselves goals.

K: I used to go to measure up and I had goals like cut down portions and do an hour of Wii fit

Facilitator: If we did a fitness club would anyone be interested?

A: Yes

G: Yes

R: Yes

M: Yes

K: Yes

P: No

Z: Not sure

Facilitator: What about healthy cookery?

All: Yes

Facilitator: What about a walking club or running club?

Z: Not running

K: Yes I think probably walking. When me and P did Gateway we walked around the park.

Z: I'd do swimming, I love swimming

K: I like swimming too

Facilitator: Any other ideas?

Z: Trampolining

K: Basketball

K: Total Fitness you can do gym, swimming, hydrotherapy pool

M: Karate

Facilitator: Some of you on Gateway have been doing weigh-ins and things like that, would anyone like a weight watchers or similar at Wirral Mencap

K: I think that'd be a good idea

Z: I'm not sure

### **Housing/ Home Life**

Facilitator: What sort of things do you do at home to help out and be independent?

R: I help with dishes, I do laundry, take bins out, I do everything

A: I don't, will do dishes

M: Mopping, take bins out now and then, gardening, some DIY

K: Clean the bathroom, mopping, hoovering, making beds, cooking

G: Cooking, bins

R: Make lunch, I make my own tea

A: Made a cook book at Gateway

Facilitator: How can Wirral Mencap help you do more at home?

Z: More help, carers at home

Facilitator: Is there any skills that would help you do more for yourself?

Z: Cleaning myself, keeping myself clean and tidy

Facilitator: Any other skills? A few people mentioned cookery? Can anyone do cooking on their own?



G: I cook with the support worker

K: I cooked with my mum and made Spaghetti Bolognese

Facilitator: Would a cookery class help you do more?

Some murmured yes's

Facilitator: Is there anything anyone else would like to learn?

K: Keeping things tidy

Facilitator: Any thoughts about the future?

Z: I'd like to live in supported living with carers, I'm hoping to get in a place soon. Not with friends, in a flat with carers to help me.

R: I want to move out next year

P: I'm waiting to move out

G: It takes a while to get the paperwork sorted out.

P: Mines been sent off

Facilitator: Is there anything Wirral Mencap can do to help you plan for the future?

SW: Helping to prioritise, bills etc

K: Has anyone got bus passes?

Everyone: Yes I do

Z: I can travel all round Wirral and Chester, Manchester, London on my own

Z: Travel training to get more people independent on buses and trains

Facilitator: Has anyone had travel training?

K: A long time ago at Wirral Met

R: I did

P: I didn't

Facilitator: What would help you learn about the buses and trains?

Z: Learning to give the right change

SW: Budgeting

K: If I get the wrong bus I have to pay

Facilitator: Yes it's good to have some money as well in case you lose your bus pass

## Personal Development

Facilitator: The next one is about doing training, getting a certificate, volunteering, paid jobs

R: I've got 3 jobs already. One job in the Floral in New Brighton, I'm an Ambassador. Second job I work in Best Bites, in the kitchen, making sandwiches, doing toasties, doing the dishes. The last job is a paid job for 2 days in a Nursing Home.

Z: I used to have a job at West Wirral riding school. I work at Leehurst as well

Facilitator: What's that?

Z: A college in Cheshire

SW: P really wanted some volunteering with animals but all he wanted to do was play with them. As soon as they asked them to muck out he said no!

P: Laugh

Facilitator: Is anyone else interested in work?

A: I'd like to do office work

Facilitator: K, you already do a lot, is that important to you?

K: Yes

Facilitator: Why is that?

K: Can't describe it

Facilitator: Do you enjoy it?

K: Yes. I do volunteering at Church, at Mencap, 2 days at Claire House shops

G: I do volunteering for Scope twice a week. I'm getting a certificate at the end of a computer course on Mondays

P: I'd like that

G: First was beginners, second is spreadsheets which we're going onto. I was lucky because the place I do it at gave me a bursary. One person didn't have to pay and it was me.

K: Last time I did work in Barnardos. Used to do a few days work then the manager went away and I didn't go anymore.

Facilitator: Is everyone doing some sort of volunteering?

A: No

P: Yes on Friday mornings at Age UK

M: No

Facilitator: Would you like to?

M: Yes

Facilitator: What do people think of training or courses?

SW: If you're going to volunteer you might do some courses

P: I do two in the week, art and cant remember the other one

Facilitator: Is anyone interested in paid work?

Z: Yes

A: Yes

### **Leisure**

Facilitator: Now we're onto the last bit. What you do in your spare time, like see friends or go to clubs and things like that. Why do you think that's important?

Z: I spend time with family. I've got three baby cousins. They're down in Norwich

Facilitator: Does anyone go to social clubs?

G: Crossbow

A: St Marys

K: St Marys

R: Tranmere Rovers, Basketball at Bidston, Monday Night at Sherlocks Night Club, Tuesday St Marys, Wednesday Drama, Thursday Rest, Friday Work, Saturday chill. In my spare time I usually go in my room for some peace and quiet

G: I go into Crossbow and see A and R going to Drama

P: Tuesday St Marys, I've started to go to a new one

M: I don't

SW: (To M) Do you want to try Sherlocks? His little sister goes there

Z: I used to go to Crossbow but I'm not going anymore

Facilitator: Why do you go to the clubs?

R: To have a laugh

K: Tuesday St Marys in Wallasey, Wednesday Dance in Pilgrim Street, Thursday Hot Wheels in Hoylake

Facilitator: Is there any other reason you go?

Z: To have a break from my mum and dad and baby cousins

K: I enjoy seeing friends

Facilitator: Why that's important?

K: To see them, say hello and ask what's going on with them

R: To socialise

Facilitator: Is there anything missing that Wirral Mencap could do? Any other clubs?

K: Enough clubs

Facilitator: Are there any times when there aren't any clubs, what about during the day?

Z: Holiday clubs for bigger people

G: People have asked me at Crossbow because it's closed for August about opening for August.

Facilitator: Any other ideas? Have people got enough to do in the day?

Z: Yes I go to college

A: All I do is lie in my pit

Facilitator: If we had more going on here in the week would you come?

SW: To be fair he does get up for Mencap

Facilitator: We've just started a drop-in lunch club at Mencap

P: I come every 4 weeks, I can't come every week

Facilitator: It's a drop in, every Monday 12pm – 2pm. You can come or not. We've been looking at more drop-in activities that you don't have to sign up for. Is that something people would be interested in?

Z: Yes

A: Me

Facilitator: What about a drop in Art Club?

K: Yes

P: Yes

M: Yes

Facilitator: So what about day trips?

Z: Yes and more holidays like PGL

Facilitator: What about the camping trip?

A: I can't go because of my wheelchair

SW: If you wanted to go I'd go, I'd be able to help you

Facilitator: So more camping trips?

Z: More indoor camping like cabins for disabled people

Facilitator: What about friends, would anyone like more friends?

Z: I've got tonnes

A: I would like to stay in a POD

P: I'm not going again, going to Pontins in May.

Facilitator: Lets talk a bit more about friends. Has everyone got enough friends or would they like more? Would anyone like to meet new people and make new friends?

R: Yes me

Facilitator: How could we help?

G: Different people coming

Facilitator: Would anyone like to find a boyfriend or girlfriend?

Z: I've got one

R: I would

A: There's a problem because they're always at home or in bed.

K: I don't think I would

Facilitator: What could Wirral Mencap do?

K: Go on the television, Take Me Out

Facilitator: Is there anything else Wirral Mencap can do?

A: No not really

Facilitator: Any other ideas?

SW: Pub Crawl

Facilitator: Would anyone be interested in going out in the evening?

K: Yes

A: Speed dating

K: Or going out for meals?

Facilitator: Would anyone be interested in that?

K: Yes

R: Go on a date to the cinema?

Facilitator: Would you like help with that?

Rory: Yes

----- *End* -----