



Digital Inclusion

What prevents people from accessing digital services and sharing their experiences of care with the Care Quality Commission (CQC)?

By HWLincs
May 2023

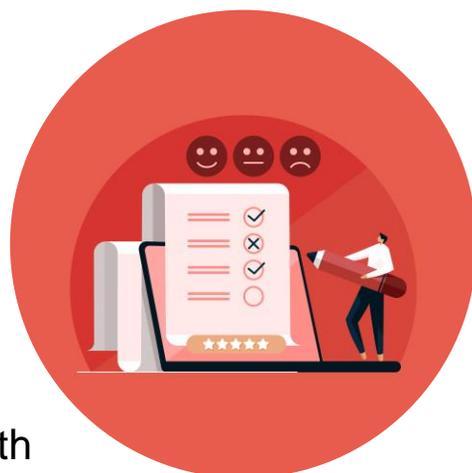
Background

Brief: 'How can CQC collect experiences of care from people who are digitally excluded?'

This insight would be gained by using a range of engagement methods which were focus groups, one to one interviews and a paper survey.

A short easy read survey/questioning framework was designed to be used during the engagement activities and consisted of core questions defined by CQC:

- Reasons for digital exclusion
- If people share experiences of care, who do they share them with and how?
- How can CQC help enable people to share their experiences with them?
- How can CQC feedback to people if they are digitally excluded?
- Are people aware of what CQC will do with the information they share?



A full copy of the survey can be seen in Appendix 1

We focused on gathering this information from the following four seldom heard groups:

Homeless

Low-income households

**Young families and
maternity service
users**

**Adults with learning
disabilities**



Executive summary of findings

- The main barriers identified to accessing digital services were lack of skills and confidence, connectivity/signal and data allowance.
- Amongst all the groups there was widespread apathy. Many did not see the benefit in sharing their experiences as they saw no change as a result.
- The majority did not feel that their opinion or feedback was listened to and valued as people saw no demonstrable change when they had shared their experiences previously.
- In some of the groups, there was a 'slight undercurrent of mistrust in the system'.
- Individuals were worried about sharing their negative experiences as they did not want to be seen as a 'troublemaker' or 'keyboard warrior' and were concerned it would affect their access to services in the future.
- Awareness of CQC, it's roles and functions was very low amongst the homeless, low-income and young family and maternity service user groups.
- Participants would be motivated to give feedback if they felt their opinion was valued and listened to and saw 'real' change as a result of sharing their experiences.
- There needs to be multiple, simple different ways in which people can provide feedback. The most appropriate method(s) was in some cases group specific.
- Overall, participants appeared to want CQC to be more proactive in driving the collection of feedback as opposed to relying on the public remembering to give feedback.

Executive summary of findings

- The following were suggested as ways CQC could **gather feedback**: (listed in no particular order)
 - **Free phone**
 - **Prepaid envelopes**
 - **Regular reminder email to support groups asking for feedback**
 - **Survey**
 - **Face to face (in person or virtually)**
 - **Directly from services**
- Connecting into 'bridging organisations', which already have trust and a relationship with these groups, such as different support groups, commissioned carer services and local Healthwatch would be beneficial.
- For any of these suggestions to have the biggest impact, issues such as apathy and seeing real change need to be addressed first.
- All groups would value hearing back about what had happened with their feedback and had changed as a result. This would make them more motivated to provide feedback.
- The following were suggested as ways CQC could **gather feedback**: (listed in no particular order of preference)
 - **Phone** (as long as the number was not withheld)
 - **Text platforms** e.g. iMessage
 - **Letter/Email**
 - **'You said, we did' style reports**
 - **Newsletter** (hard copy)
 - **Face to face** (both in person and virtually) **via support groups and carers**
 - **Via bridging organisations/groups** such as local Healthwatch

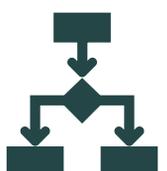
Recommendations

- Increase awareness of CQC amongst the population, its role and rationale for gathering feedback on services. This could be done by advertising on noticeboards in places where these seldom heard groups visit e.g., hostels, libraries, community groups or at services. Also, there needs to be greater promotion of what the CQC does with the data it collects.
- Ensure people are informed about what happens with their feedback **and the changes that have occurred as a result. Doing the latter would go some way to address the apparent widespread apathy and motivate many to share their feedback.**
- Trust and relationships needs to be built with seldom heard groups. Many participants did not feel their feedback was listened to or valued.



From the focus groups, the below recommendations will only increase the amount of feedback shared if trust and apathy are addressed first.

- There needs to be more opportunities/reminders to give feedback – e.g., reminders on the bottom of appointment letters, at services or emails to local groups.
- There needs to be multiple, simple different ways in which people can provide feedback. The most appropriate method(s) was in some cases group specific (e.g., those with learning disabilities preferred giving feedback face to face, whilst those who were homeless preferred the idea of a free phone number or prepaid envelopes).



Recommendations

- The following were suggested as suitable ways to provide feedback to the CQC:

Free phone service

Prepaid envelopes

Face to face (in person and virtually)

Regular email to e.g., community groups asking for feedback

A survey

Gather feedback directly from services

- Connect into 'bridging organisations', which already have trust and a relationship with these groups, such as different support groups, commissioned carers services and local Healthwatch would be beneficial.
- Any digital methods such as online forms need to be simple and quick to use to ensure that little phone data is consumed and those with minimal digital skills/experience can complete it.
- The preferred method of CQC feeding back did vary from group to group with the following methods being suggested:

Phone*

Text platforms such as iMessage

Letter or email

'You said, we did' style reports

Newsletter (hard copy)

Face to face via carers or support groups

Via 'bridging organisations' i.e., local Healthwatch

*as long as the number is not withheld

Why did we choose these groups?

Adults with learning disabilities

- In November 2022, HWLincs attended a Voices for All meeting (a local group for service users with mild to moderate learning disabilities, their carers and other professionals).
- Service users verbally shared their predominantly poor experiences of annual health checks, as well as poor communication and use of the 'all about me' document, particularly in hospitals.
- Voices for All had not previously shared the above experiences with us, this identified to us that working with them on this project would be extremely beneficial.

Young families and maternity service users

- Lincolnshire tends to have more younger parents than other areas of England as well as a higher-than-average number of children born into absolute and relative low-income families*.
- Discussions with the local NHS lead for maternity services highlighted 'cost of living' struggles for young families - impossible choices are being made e.g. deciding to pay for travel to attend essential appointments and anti-natal classes, or pay the bills and buy food.
- Our discussions will explore whether they have made a choice to reduced spending on broadband to enable them to pay for travel expenses to health appointments, and how this has impacted their health and ability to stay connected.

[*Office for Health Improvement and Disparities - Fingertips Public Health Data - Child and Maternal Health 21/22/23](#)



Why did we choose these groups?

Low-income households

- Boston and East Lincolnshire are two of the most deprived areas in England (formally identified as low-income areas)*.
- Barriers to digital services in low-income households can include:
 - Digital poverty, limited access to equipment, and service e.g. pay as you go mobile rather than contract
 - Poor digital connections (a real issue for some living in East Lincolnshire, potential digital divide in the county)
 - Lack of skills and understanding (particularly relevant as there is lower than average educational attainment within these areas)
 - Lack of motivation and confidence

Homelessness

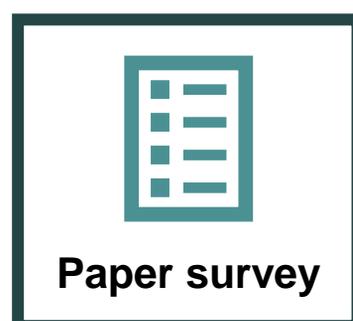
- This group could be affected by both digital exclusion and poverty.
- We also know through our Healthwatch work that homeless people rarely share their healthcare experiences.
- This project was an ideal opportunity to increase awareness amongst homeless people of how they can share their experiences of health inequalities and ways they can do this regardless of where they are living.

[*Ministry of Housing, Communities & Local Government – Indices of Deprivation 2019 – Local Authority Dashboard](#)



Engagement Approach/Methods

- All participants were informed about the role of CQC, the importance of sharing experiences and how speaking up can make a difference.



- Paper copies of the survey were also supplied.
- This ensured that the views of those who did not feel confident or comfortable participating in a focus group or interview were still recorded.

How did we engage with our groups?

As a local charity, with links across Lincolnshire and our borders, we have relevant and enduring connections (which we are always developing, reviewing and building on) that enable us to link in with a large number of communities and localities.

Group	Engagement approach	Number of participants
Homelessness	Focus group	7
Adults with learning disabilities	Focus group 1:1 interview	9
Low-income households*	Focus group	5 (+ 9 under 18)
Young families and maternity service users*	2 focus groups	10 3

**Many of the individuals in these two groups overlapped e.g. the young families could also be classified as low-income households.*

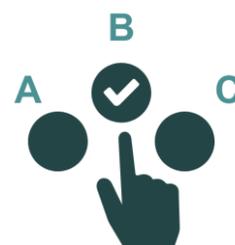
We have not named the specific groups we engaged with to protect their and individuals' anonymity.

A full breakdown of the demographics of participants can be seen in Appendix 2.

Findings – Homelessness

Barriers to using digital services

- All had access to smartphones but access to WIFI was patchy. Hostel WIFI is erratic especially when many people are using it. Furthermore, some websites and words are blocked which can stop use of legitimate websites.
- Data costs limit activity (e.g. data would be used for claiming benefits and accessing DWP as opposed to sharing feedback on care).
- Some were aware of social tariffs and accessed Vodafone scheme (free sim with 20GB of data) via local library.
- When street homeless, access to charging and connectivity are an issue but usually libraries, cafes and some charities will charge devices and allow use of free WIFI.



Sharing experiences of care

- Not sure who to complain to or where to start. If relying on their own limited phone data, sharing experiences of care would not be a priority.
- Those that did share their experiences of care did so to their friends and family.
- Many were worried about and felt uncomfortable sharing their experiences as they feared being kicked out of the service or clinic (or that their access/treatment would be different as a result).
- They were frustrated that their voices are not heard and taken seriously.
- No issues registering with GP as currently all at hostel and registered. Hostel has a in house healthcare team who provide a range of services.



Findings – Homelessness

Communicating with CQC

CQC gathering feedback

- Free phone number or prepaid envelopes with feedback form could be used.
- More publicity around CQC and their role (advertise on/ in hostels and public noticeboards about sharing feedback) would encourage people to share their feedback.
- Practical advice on how to immediately resolve issues would be useful.
- **General concerns were raised around waiting times for A&E, clinics and GP appointments.**



CQC feeding back

- **All agreed they would want to hear back from CQC and the actions taken regarding the feedback shared. This would motivate them to share their feedback.**

- The following were suggested as the most effective ways for CQC to feed back:
 - Phoning people to update would be useful as long as the number is not withheld
 - Text, iMessage or similar dependent on platforms could be used
 - Letter or email could also be used, participants were happy to provide a name and email for replies
 - Reports in the style of 'You said, We did' (easy read format)
 - All expected CQC to use their feedback lawfully and in compliance with GDPR, feedback would be destroyed once processed and no longer needed



Findings – Adults with learning disabilities

Barriers to using digital services

- Most had access to digital equipment. However, the majority (7/9) needed support to be able to use it. Lack of skills and confidence were identified as the main barrier preventing or limiting the use of digital services.
- Internet access was temperamental and slow.
- As devices were shared by residents, there were concerns around confidentiality when sharing personal information.

Sharing experiences of care

- Most recognised the importance of sharing their experiences but did not necessarily recognise that sharing positive feedback was equally as important as sharing negative feedback.
- Privacy concerns and the person providing support to give feedback were two of the key barriers in sharing feedback. Sometimes residents would want to provide feedback on those providing them the support to provide feedback and were unsure of how they could do this.
- Most currently shared their experiences of care with either their support workers or their families in person or over the phone. Once they have done this 'they forget about it and moved on with their day'.
- A routine reminder/opportunity to share feedback such as a monthly email asking for experiences would be beneficial.

One staff member said, “perhaps we should ask every time how was that for you?”

- Upon sharing their feedback with CQC they would expect their feedback to be acted on and see improvements in care quality. This would motivate them to share their feedback.



Findings – Adults with learning disabilities

Communicating with CQC

Gathering feedback

- The preferred methods of communication between themselves and CQC were face to face (including Zoom and MS Teams) either individually or as a group, some support would be required to do this or
- A regular email (from a trusted email) asking routinely for feedback or;
- A survey (digital or paper) again support would be needed to complete this
- Did not like the idea of a text – this was impersonal, and it is hard to understand tone and meaning of a text
- Mixed opinions on the use of incentives such as gift cards to encourage people to share feedback.



CQC feeding back

- The best way for CQC to feedback to this group would be in person or digital face to face meeting or via support staff and carers.
- Currently the group rarely hear what has happened as a result of them sharing their feedback. When this has occurred, it tends to be when they have shared their experiences as a group.



A Case Study – An adult with a learning disability

The information shared during this 1:1 Interview echoed the themes and ideas raised in the focus groups.

- Support is needed to enable them to use digital services.
- They tell their family or staff in person (as they lip read) when they've had a bad experience of care.

“I don't think about telling people my good experiences as I think that is people doing the job they are supposed to.”

- They share their experiences because they want someone to do something about it and improve it for next time.

“I told them once that I had been to see the Dr and they had told me there was something wrong with my throat and gave me a medicine, but when I went back a different Dr told me it was something else, this just confused me and made me worried. I told the staff but they didn't do anything about it.”

- When asked what would encourage them to share their feedback, they responded as follows:

“Knowing that they actually use my feedback and that it will improve my services.”

- The best ways to communicate with CQC would be 1:1 face to face or via Zoom/ MS Teams (both of which would require some support).

“The other idea I had was for CQC to send us regular emails, that we know come on a certain day every month and ask us if we have any experiences we want to tell them about.”

- They really valued hearing back from CQC about what has happened as a result of sharing their feedback. They were unaware of what CQC does with the feedback.

“I would like to know who they have spoken to about my feedback and what they have done about it. Showing that they have helped me would make me feel happy and that my voice is actually important.”

Findings – Low-income households

Barriers to using digital services

- Mobile signal and quantity of data
- Lack of information (both how to use digital services and share feedback) and skills



Sharing experiences of care

- Very low awareness of how to report a problem and CQC (e.g. does CQC apply to everyone? Is it possible to get in touch 24 hours a day?)
- Lack of opportunities/reminders, confidence and skills were the barriers identified to sharing feedback.
- Also, apathy ('nothing ever changes, so what's the point') appeared to be stopping people from sharing feedback – especially with a national organisations.
- People questioned whether their feedback would make a difference, especially going to a national organisation.

"Sometimes you might feel like if it's that national, would they actually listen to you?"

- Others were put off sharing feedback by long, complicated forms – especially if they were online.

***"How simple is the form?
That's sometimes the
frightening thing."***

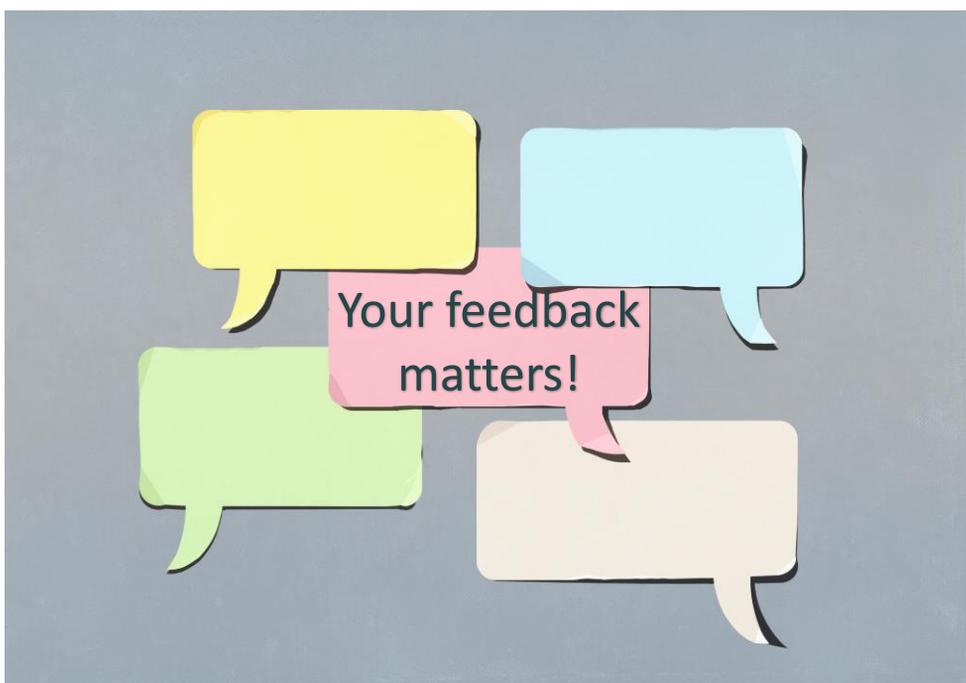


Findings – Low-income households

Communicating with CQC

Gathering feedback

- The group identified the following as being the best ways for them to share feedback:
- Automated phone form or talking to someone on the phone (“talking gets straight to the point and is more direct”).
- There was caution around the use of email, as participants were worried about being a “keyboard warrior” and shared “I get madder and madder as I write”.
- Many appointments are booked over the phone or via letters – this could be an opportunity to remind people to give feedback.
- The group agreed that having the likes of Healthwatch as an in between would be more appealing and thought contacting a local Healthwatch would be more effective.
- The group was unsure of what happened to the information they shared. It was felt that too many people want the same information and there appear to be a mistrust of the system. Participants did not want everyone ‘knowing their business’ and were concerned over how and for how long the information was stored .



Findings – Young families and maternity service users (*Group 1*)

Barriers to using digital services

- There was a mix between participants who could/could not access/use digital services.
- For those who could not, there was a few reasons for this such as finding them impersonal or lack of skills and knowledge on what to do. The latter can be “frustrating and result in being misinformed”.
- Some wanted to speak to someone in person and are finding this increasingly difficult.

Sharing experiences of care

- Again, there was a very low awareness of CQC.
- When sharing their experiences of care, this group would also do so directly to the service e.g., social worker or GP surgery.
- Some participants had previously shared their experiences with PALs or the practice manager.
- However, they did not feel listened to or that their concerns were taken on board and acted upon. Indeed, they felt dismissed for sharing their concerns



- They did not want to keep repeating themselves.
- In this group there was also high levels of apathy – ‘nothing ever changes as a result’ of sharing their experiences.
- They were only interested in sharing their experience if something actually changed as a result.

Findings – Young families and maternity service users (*Group 1*)

Communicating with CQC

Gathering feedback

- Again, many felt that CQC should get the feedback directly from services i.e., the group shared their feedback directly with the service, who should then share this feedback with the CQC. Instead of the service using having to repeat themselves and tell the service and the CQC.

Participant gives feedback to

service

gives feedback to CQC

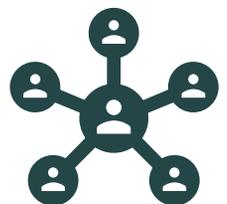
CQC feeding back

- The best way for CQC to feedback to this group would be via the community group.

Findings – Young families and maternity service users (*Group 2*)

Barriers to using digital services

- Cost and access to SMART phones was raised as a concern – (could not afford the latest equipment).
- Most had basic phones just to call and text. For anything else, such as searching for information they relied on family members.
- Some could not read or write very well.



Sharing experiences of care

- Again, there was a very low awareness of CQC.
- When sharing their experiences of care, they too would share it directly to the service e.g. social worker or GP surgery.

Findings – Young families and maternity service users (*Group 2*)

Sharing experiences of care

- They did not want to keep having to repeat themselves e.g. having to tell the service and tell CQC about their experience.
- There was also high levels of apathy amongst this group – ‘nothing ever changes as a result’ of sharing their experiences e.g. ‘ease and timely access to services never improves (in fact it is becoming increasingly harder to access services)’.
- They felt (based on previous experience) that professionals were not truly interested in what they have to say and their feedback.
- They also did not want to be seen as a ‘troublemaker’ if they shared or spoke up about their negative experiences as they feared this would make it even harder for them to access the support and help needed.
- They would be more inclined to share their experiences if they actually felt their opinions mattered and were listened to.
- An incentive (e.g. a gift card) would also make them more likely to share their experiences.

Communicating with CQC

Gathering feedback

- Many again felt that CQC should get the feedback directly from services (this would avoid duplication and repetition).
- The group was unsure of what happened to the information they shared, to many people want the same information, mistrust of the system (did not want everyone knowing their business) and concerns over how and for how long the information was stored.



CQC feeding back

- The best way for CQC to feedback to this group would be in person or via a hard copy newsletter.



Closing Statement and Acknowledgements

HWLincs and Healthwatch Lincolnshire would like to thank ...

- The Care Quality Commission for providing this opportunity to engage with these groups and present their voice to you.
- The staff and volunteers at HWLincs and Healthwatch Lincolnshire for supporting the work.
- The groups and organisations that were pivotal to making these interactions happen.
- And perhaps most importantly those people across all the selected cohorts who took the time and energy to contribute to the discussions and findings.



Thank you!

Appendix 1 – Survey/Questioning Framework

- 1. What is preventing you from being able to use digital (online) services?** *For example, you may not have a device that connects to the internet, no mobile data/internet is included in your phone package, you do not know how to use or access online services.*
- 2. What stops you from sharing your experience of care e.g. the doctors, hospital or social care with the CQC?** *These experiences may be good or bad or both.*
- 3. Who do you tell if you've had a good or bad experience of care?** *For example, who would you tell if you had a bad experience at the hospital. How would you tell them this?* *For example, I would tell my friend or the leader at the group session I attend if I had a bad experience at the hospital*
- 4. What would be the best way for you to share your experiences with CQC?** *For example by sending them a text, calling a free number or putting something in the post (free post)*
- 5. What would be the best way for CQC to communicate with you?**
- 6. What would you like (expect) CQC to do with the feedback you share?**
- 7. What would make you more likely/encourage you to share your experiences of care?**
- 8. Do you know what happens/would happen to the information you share with CQC?**

Appendix 1 – Monitoring (demographics) Form

If you do not want to fill this in, please tell us why:

- I do not see why they need all this information
- I do not want someone having all this information about me
- There is not point in filling it in
- Other: please tell us more:

1. What is preventing you from being able to use digital (online) services?

- I am able to use digital (online) services
- Lack of skills and confidence e.g. It is too complicated
- Financial barriers e.g. It is too expensive or I spend my money on other things
- Physical barriers e.g. I do not have any internet on my phone, I have no phone or laptop or my connection is too slow
- Trust e.g. I am worried about what will happen to my information/data
- Fear e.g. I have a fear of making phone calls or using the internet
- Motivation e.g. I have no interest in using online services
- I do not want to access services online
- Other, please tell us more:

2. What is your age?

- 18 – 25
- 26 – 35
- 36 – 45
- 46 – 55
- 55+
- Prefer not to say/Not sure/Not known

3. What is your gender?

- Woman
- Man
- Non-binary
- Intersex
- Prefer to self-describe:
- Prefer not to say/Not sure/Not known

4. How would you describe your ethnicity? E.g. White: British, Black: British African, White: Eastern European

- Prefer not to say

5. What is the first part of your postcode?

- No fixed address
- Prefer not to say

6. Do you have a disability?

- Yes
- No
- Prefer not to say

7. Do you have a long-term health condition?

- Yes
- No
- Prefer not to say

8. Do you look after a family member, partner, friend or neighbour who needs help because of their illness, frailty, age, disability, a mental health problem, addiction or cannot cope without support?

- Yes
- No
- Prefer not to say

9. Which of the following do you receive as income? (Tick all that apply)

- Wages/Salary
- Income from self-employment
- Disability benefits (e.g., Attendance Allowance or Personal Independence Payments)
- Means-tested benefits (e.g., Universal Credit, Tax Credits, Housing Benefit, Pension Credit)
- Other benefits
- State retirement pension
- Occupational/private pension
- Student loan
- Other, please tell us more:
- Prefer not to say

Appendix 2 –Who shared their views?

	Number		Number
Group		Gender	
Homelessness	7	Woman	21
Adults with learning disabilities	9	Man	6
Low-income households	5*	Ethnicity	
Young families and maternity service users	13	White: British	27
Age		I have a disability	17
18 – 25	5	I have a long-term condition	13
26 – 35	9	I am a carer	12
36 – 45	8		
46 – 55	3		
Source of income		Postcode	
Wages/salary	3	PE11	2
Disability benefits	19	PE21	9
Means-tested benefits	13	PE23	3
Other benefits	3	PE25	1
Maternity pay	1	LN1	1
Partner's salary	1	LN2	7
		LN12	1
Rough total income		LN13	3
Less than £15K	16		
£21,000 - £25,000	1		
£35,000+	1		

Please note that not all participants completed the demographic questions and some only partially answered these questions. May did not give a rough total income.

There was an overlap between many of the groups especially low-income households and young families.

*5 children under 18 were also present