

Adult Learning Disability Service in Gwynedd

Results of user engagement survey

During the spring and autumn of last year, we engaged with users of our learning disability services, and their families and carers, to ask your views on the kind of changes that will be needed in future.

A questionnaire was sent to you all, and we held meetings in different areas explaining the changes that will be needed in terms of:

- The goal of ensuring that people with learning disabilities can live a life that is as independent as possible with the right support
- A new law, the Social Services and Well-being (Wales) Act 2014, which came into force in April 2016
- The need for services to be provided in the most effective way possible – as Gwynedd Council gets less money from the Government, we have to spend it in the best way.

Of the questionnaires that were sent out, a total of 25 were returned. A total of 25 people also attended meetings held in Pwllheli, Porthmadog, Dolgellau, Caernarfon, Bethesda and Bangor.

This document is intended to

1. Discuss the kinds of changes that will be needed for the reasons outlined above.
2. Present a summary of the kinds of responses received, on the forms and at the meetings.
3. Suggest the next steps for moving forward.

Part I

The need for change

When the Social Services and Well-being (Wales) Act 2014 came into force in April this year, it placed additional responsibilities on councils such as Gwynedd in the provision of services.

In particular, the Act will mean a stronger voice and more control for our service users, and also more rights for carers. We will also be required to help people to get more involved in the planning of services.

The key aim of the Act is to help people to live as independently as possible with the necessary support. This is not new in itself, as this is already one of our key objectives as a Council as we collaborate with the Welsh Government. The new Act will underpin such objectives.

It will affirm that all those who have a learning disability are full citizens with the same rights as everybody else. The Act should strengthen our endeavours to ensure an opportunity for all, whatever their abilities, to reach their full potential. We want to ensure that individuals contribute to their community and are part of it, and also have the opportunity to have services in their community.

What makes the task more difficult is that the changes have to be achieved at the time when the Council is receiving less money from the Government. Therefore, in order to safeguard our services, it is essential that the Council spends its money in the best possible way.

As we work towards achieving the objectives, some changes have already been made. These include helping people to have work experiences and volunteering experiences and also to participate in group activities. We also make more use of assistive technology, which is helping individuals to become more independent.

We were eager to have your views on these changes and your ideas for other changes in future. Your response has been invaluable as we prepare for the changes.

Part II

A. The Questionnaires

Of the questionnaires that were sent out, a total of 25 were returned.

Respondents had an opportunity to answer a total of eight questions. The first question involved a description or the role of the respondent; questions 2, 3, 4 and 5 were multi-choice ticking of boxes; questions 6 and 7 invited comments and question 8 asked for a willingness to take part in further research.

To address each question in its turn:

1. In what capacity are you responding to this questionnaire?

Of the 25 who replied, 8 of them, almost a third (32%) were users themselves, and 11 of the others (44% of the total) were a relative, carer or friend. Of the remainder, 3 were staff members working in the health, care and well-being sector, 1 was a member of Gwynedd Council staff, 1 was a service user under 18, and 1 did not answer.

2. Do you understand the three reasons why change is needed in the way learning disability services are provided?

In order to assess respondents' understanding, they were asked to reply separately to the three questions.

23 out of the 25 (92%) said that they understood the first reason given, that is to ensure that everybody is able to live as independently as possible. Only one said that they did not understand, and one other did not reply.

The proportion who noted that they understood the other two reasons was somewhat lower.

18 (72%) said they understood the second reason, which was to comply with the law. Four (18%) said that they did not understand; 2 (8%) had no opinion, and 1 gave no response.

19 (76%) said they understood the third reason, which was to meet the financial challenge. Only two (8%) said they did not understand. Two had no opinion and another two did not reply.

3. Do you understand the Council's objectives for learning disability services in the future?

When asked if they understood the Council's objectives, five replies were offered, and it was clear that a high proportion understood each one of these.

22 out of 25 (88%) said they understood the first objective, which was to offer services in ways that helped people to live as independently as possible.

21 (84%) understood the objective of offering services that enable people to reach their real potential.

22 (88%) also understood the aim of concentrating on people's skills and strengths to be able to live as independently as possible.

A slightly smaller proportion (76%) understood the aim of targeting services and scarce resources for people who need them most, with 3 (12%) not understanding, 2 with no opinion and 1 not replying.

84% understood the aim of encouraging and supporting local communities to do as much as possible.

4. What do you think of the following changes that have already been made?

When asking about views on the changes that have already been made, four examples were offered for respondents to be able to describe them as Very Good, Good, Bad, Very bad, No opinion or Don't Know / understand.

The responses were quite positive to the first change – which was to help people to get work with local businesses in the community. 80% believed that this was either good or very good (44% very good, 36% good). Only one believed that it was a bad thing.

Whilst the aim was praised, some concerns were expressed. One said that many businesses would need financial support before they would take on a person with learning disabilities. One respondent was concerned that this could raise people's hopes too much and another comment was "excellent idea, but very expensive as 1:1 support would be needed".

Opinion was more divided about the use of telecare and assistive technology. Fewer than half of the respondents had any firm opinion, with only one believing that this was a bad thing. Seven (28%) believed this to be a good thing, and 4 (16%) believed it was very good. Five (20%) had no opinion, 4 (16%) did not understand and another 4 (16%) did not reply.

One respondent said that telecare would be good for some but that their son could not use it, and another said that only a small number could benefit from this.

The majority of respondents were pleased to see more support services delivered to people in a group, with 7 (28%) saying this was a very good thing and 9 (36%) saying it was good. Only one saw this as a bad thing, 2 (8%) had no opinion, 3 (12%) did not know or understand and 3 (12%) did not reply.

More than one, however, stressed that this would not be suitable for everyone. One had a son who hated being in a group, and another one said that the group activities had not been so successful as it was difficult to motivate individuals with different interests. Another one accepted that this was a good idea, but wanted to know if it were possible to revert to 1:1 if it did not work.

Just over half approved the development of new accommodation models – 5 (20%) Very good and 8 (32%) Good. Two (8%) believed this was a bad thing, and 1 (4%) believed it to be very bad. A total of 9 (36%) either had no opinion, did not know or understand or did not reply.

Comments received in relation to this question were that there was not enough information about these models and that it was too early to say. One expressed concern about “creating ghettos”.

5. What do you think of the other potential solutions for the future provision of learning disability services?

A total of eight options were presented for respondents to give their views, with an opportunity to give the same descriptions as in question 4.

A positive response overall was received for each one of the suggestions, with the majority of respondents describing them as either Good or Very good. There was some variation however in the degree of enthusiasm for these proposals.

Three quarter of the respondents believed that the idea of helping people to join with groups and activities in the local community was either good or very good (9 -36% very good, 10 – 40% good). Two (8%) believed this to be bad, and the others were either with no opinion or did not reply.

One respondent stressed the need for much more support and training so that this could be done successfully. “Appropriate support needed” was another comment, and another stressed the need for Council departments to liaise with each other.

There was less enthusiasm towards helping people to organize their own activities within groups. Seven (28%) believed that this would be very good and another 7 (28%) believed it would be good. Three (12%) however believed this to be bad, and 1 believed it to be very bad. Another 7 (28%) were either without any opinion, did not know or understand or did not reply.

According to one respondent, the idea was fine for those who could do this, but that it was not possible for those with the most intensive needs. A shortage of funds was another respondent's concern: "Good idea, but who will develop it with less money in the budget?"

Another respondent was more critical: "What? Individuals who need support with all aspects of their lives – how are they going to organise activities?"

Almost three quarters supported the idea of developing a friends scheme within communities, with 10 (40%) believing this to be a very good thing and another 8 (32%) believing it to be good. Only one believed that this was a bad thing, with 4 (16%) with no views, 1 who did not know or understand, and 1 who did not reply.

The lack of money was a concern for more than one respondent. One said that training volunteers is costly and that there is a dearth of volunteers. Another one asked if there had been adequate research.

Just over half (13 – 52%) believed that it was a very good idea to recruit more Adult Placement Scheme enablers, and another 5 (20%) believed it to be good. Nobody saw this as a bad thing, whilst 3 (12%) had no opinion, 2 (8%) did not know or understand, and 2 did not reply.

One respondent stressed that there was a need to ensure the suitability of these enablers.

The idea that was most enthusiastically welcomed was to develop different opportunities to give respite to families and carers. More than half (52%) believed this to be a very good idea, and another 28% believed it to be good, giving a total of 80% positive responses. Nobody believed this to be a bad idea, but 3 (12%) had no opinion and 2 (8%) did not reply.

One said that this was a good idea but that they needed to know more to see how relevant what would be offered will be. Another said that it could be costly.

A substantial majority was also in favour of developing daytime opportunities, with 52% believing this to be a very good idea and 24% believing it to be good idea. One (4%) believed this was a bad idea, whilst 2 (8%) had no opinion, 1 did not know or understand and 2 did not reply.

Financial worries were also prevalent. “Good idea, but who pays?” one asked. “Fine in theory but has not been done adequately to date” was another comment.

Opinion was more divided about making greater use of direct payments so that people could choose and arrange their own care. Just over half expressed their approval (32% seeing it as a very good idea and 20% as good). Three (12%) believed this to be a bad idea, and 1 (4%) a very bad idea. Four (16%) noted that they did not know or understand the question, and 3 (12%) did not reply.

“Direct payments is not the answer” was one respondent’s opinion, and another one stressed the need for more research.

There was some uncertainty with the idea of developing different accommodation models, although nobody saw this as a bad thing. Ten (40%) were of the opinion that this was a very good idea and another 4 (16%) believed it to be good. Three (12%) had no opinion; 4 (16%) felt that they did not know or did not understand; and another 4 (16%) did not reply.

One respondent said that more information was needed before the question could be answered, and another was concerned that any changes can be traumatic for people with learning disabilities. The same respondent also said that it was too early to judge Pant yr Eithin, claiming that only 4 are there up till now.

6. What other ideas do you have on how learning disability services can be delivered in future?

This question asked respondents to suggest their own ideas. Responses were received from 15, which is 60% of those who returned the questionnaire.

Here are some of the ideas that were proposed.

- Day trips and weekends away – which would give a break between holidays
- Shopping trips
- Football for the disabled
- Courses on life skills and housework and financial responsibility
- More group activities and days out. Opportunities to meet people, such as the Gateway Club.

Others highlighted specific needs.

One stressed the need for more care with autistic adults, saying that groups were not suitable for them because of their lack of communication skills.

Another one said that learning disability and physical disability should be treated equal, suggesting that more money was available for learning disability.

Another respondent praised the provision up to 18 years old, but was concerned that young people were then forgotten. The same respondent said that the same provider was not suitable for everybody. Accepting the need to promote independence, the respondent said that their relative benefited from being on work experience in Tesco every Tuesday.

The lack of suitable homes was the worry of one user who suffered from Asperger's Syndrome. The user was concerned about the bedroom tax but welcomed the ILF and direct payments.

The financial situation caused concern for several.

"Happy with the provision, but worried about the future" said one, questioning how effective volunteers can be. The same person also said that it was difficult to judge what will be needed without knowing how much money will be available.

More research and assessment needed to be done according to one respondent, who said that the ILF payments had not been handled well up to now. The same respondent also argued that different solutions were needed for different parts of Gwynedd.

Another stressed that there was a need to focus on the quality and continuity of care, however much money was available. The same person also stressed the importance of the relationship between the client and the carer.

One respondent proposed the idea of establishing a panel of parents/relatives to discuss the future of services. "This is the only satisfactory way of consulting," the respondent said, and added that more links were needed between the education and social care, adults and well-being departments.

7. Do you have any other questions or comments?

Many of the same issues as in the previous question were also raised in this question.

There was a need to help workers learn more about autism, according to one respondent. Specialist staff are needed in special needs, said another.

Another respondent welcomed respite periods, but stressed the need to have the service within reach. Their experience was having to travel afar.

One respondent's criticism was that the options were involved with people with less severe learning disabilities. "Those with the more serious conditions will need the same kind of care as before," said the respondent.

Financial worries were a constant theme:

"Many of the ideas are good, but money is needed for them to be realised," said one. "It's clear that there is more emphasis on volunteers, but where will the volunteers come from?"

Another one said that he understood the objectives, but how could the above be achieved with less money? "The nature of society has changed and communities are less willing or are with less money to volunteer," he said.

One respondent stressed the need for Gwynedd Council to safeguard the money for individuals with a learning disability.

"Encouraging semi-independence is excellent but support is essential and it can be expensive," the respondent said. "It is a cause for worry to think how the Social Services are going to continue to work with less money – very difficult choices."

In saving money, there was a need to look for the people with the greatest need, not those whose parents filled questionnaires, according to one respondent, who claimed that "many parents are bleeding the system".

One relative was asking for more information: "How do you support people to live as independently as possible? How do you ask the local community to help adults with a learning disability?"

8. If you would like to be a part of any further research, please note your contact details below.

14 (56%) replied that they would be willing to be part of further research work. Of these, 13 gave their address, and 11 their telephone number, but only 5 gave an e-mail address.