



REPORT ON OUR PRE- BUDGET MEETING 9TH JULY 2018

The National Platform of Self Advocates held a meeting on the 9th July in the Academy Plaza Hotel, Dublin to consult with our members on how money should be spent in the 2018 budget.

[The National Platform of Self Advocates](#)

Contents

1. Summary.....	2
2. What is important to us in the next budget?	2
3. Detailed responses to the questions.	4
Question 1 - What's important to us?	4
Question 2 - What's stopping us from living an ordinary life?	5
Question 3 - What support do we need?	7
Question 4 - What can be improved?.....	8
Question 5 - How should the government spend our money?.....	9

1. Summary

The National Platform of Self Advocates held a pre-budget meeting with our members on Monday 9th July 2018 in the Academy Plaza Hotel, Dublin. This meeting is part of our research and consultation with Minister Finian McGrath's office.

The meeting was attended by 47 self-advocates and 23 supporters.

Steering committee members of the National Platform of Self Advocates facilitated discussions by self-advocates. Note takers recorded what people said.

The following 5 questions were given to guide the discussions:

Question 1. What's important to us?

Question 2 - What's stopping us from living an ordinary life?

Question 3 - What support do we need?

Question 4 - What can be improved?

Question 5 - How should the government spend our money?

Minister Finian McGrath spent some time listening to the discussion at each table.

This is the feedback from the self-advocates.

The feedback from supporters is different and is reported separately.

2. What is important to us in the next budget?

1. Nothing about us without us: We need to have our voices heard. We need an independent group to advocate for our rights. The National Platform of Self Advocates does this work well. We want the Platform to be able to expand its work to local areas.

We want the government to fund the National Platform of Self Advocates for the next 5 years.

2. Housing: Some of us are waiting for years for houses that our service providers promised us. Some of us moved up the housing lists but no accessible houses were available. Some of us have to move out because our houses need to be adapted.

All new houses should be built as accessible houses.

3. Transport: Lack of transport means we are isolated. It is a very big problem in rural areas. We rely on family and services and can't have an independent life without them. Taxis are too expensive.

There needs to be more spending on rural transport.

Intercity bus routes need to be made accessible.

We want a voucher scheme for taxis.

4. Employment: People with disabilities find it very hard to get paid work. When we get jobs, we are often paid less than the minimum wage. Non-disabled workers are often given hours ahead of us.

We want job training that gives us a job afterwards.

We want more job coaches.

We want to be able to work more hours for more money and to keep our Disability Allowance and medical card.

5. Education: There aren't enough education opportunities for people with disabilities when we leave school. The training that we do doesn't lead to jobs. Sometimes we do training courses because there is nothing else to do.

We want places on ordinary apprenticeship schemes.

We want support to go to ordinary colleges and universities.

We want SNAs for further/third level education.

6. Personalised budgets: We want to have control over the supports we get. We want to have real choice in the supports on offer. We want lots of training to understand how personalised budgets will work.

We want training in budgeting.

We want access to trained independent brokers.

We want examples of real choices.

7. Technology: New technology and the internet can help us be less isolated.

We want support to have internet access in our homes.

3. Detailed responses to the questions.

Question 1 - What's important to us?

Transport

Transport in rural areas is very important, some people rely on parents to provide transport if we don't drive.

We want to be able to travel independently.

Without proper transport we can't get jobs, go to training courses or meet our friends. We need better transport (especially rural transport) or we need a taxi scheme. If we don't have transport we are isolated. Transport in the evenings is important. Once the service finishes we have no transport to go and meet friends.

Employment

We want to be paid for more hours of work.

We see our hours being cut – some of us had full days in the past, now we have shorter days.

We want real, paid employment – not tokenism.

We need to be job ready, we need job coaches and support people to develop our skills. We need the wider community to be supported to include us.

In short, we need better opportunities and supports to get ordinary jobs.

Accessibility

Accessible buildings, fire exits etc and accessible information are important.

Housing

There is not enough housing and housing is not adequate.

There aren't any houses being built for us. All houses should be accessible.

The right to live with who you want to and where.

Community Living needs to be planned and proper supports need to be in place.

Our Voice

The National Platform of Self Advocates is important to us.

We want our voices heard and to be listened to. We want to speak up for ourselves. Sometimes we can't get a word in edgeways.

We want to do the talking, not family or staff.

It can be hurtful when others talk for us.

We need to be listened to at events like this. Every Government department should hold consultations with us. We want more support to go to meetings about us. We are using all our own money for taxis.

Choice

We want to be able to choose where we live and who we live with. We need flexible supports with staff responding to our preferences. We need the right to

make our own choices. We need to be able to make informed choice. We want to do advocacy works. We need personal budgets.

Community

More staff to help us to go places.

We want to be independence.

Using our communities and being included in the community.

Relationships

We need freedom and support to meet friends.

To have a boyfriend.

We need a social life – we want to be able to go out more. Once staff finish work for the day we are left isolated. Some of us are sent to bed when we want to go out for a walk with friends or aren't allowed to invite our friends over for a meal or drinks.

Family and the circle of support are important to us.

Other

People have a fear of losing their DA and medical card.

We are worried about getting older – where will we go when we retire from our workshops or day services?

Question 2 - What's stopping us from living an ordinary life?

Housing

There's no movement on housing – we are promised a house by the service and it never comes, we are on waiting lists 11 years in some places (Wexford) and are stuck in residential institutions. Houses come up but then are delayed again because they need to be adapted.

HIQA – housing standards are so high that services spend loads of money doing repairs, money should be spent on transporting the person to activities instead.

Employment

It's hard to get experience, there aren't enough job coaches, it can be hard to build confidence, working can be bad for your health (anxiety caused by lack of support or discrimination/bullying). We can't get paid work, one person at the meeting is only getting 9 hours paid work between 2 jobs. There aren't enough training, apprenticeships or jobs for people with intellectual disabilities.

Transport

People are stuck if they live in the country. We rely on ageing parents for transport.

Taxis are too expensive.

We are isolated because of transport. Lack of rural transport means we rely on taxis. A lot of our money goes on taxis

Public transport isn't accessible from city to city. There is no information at bus stops, we need visual timetables to show when the next bus is coming and if there are any delays.

We rely on parents for transport – when they are away we can't go anywhere.

We often miss out on our day service if there is no transport to bring us.

People need support to get driving licences.

Internet Access

Most services don't let us have WiFi. We are adults and should be supported to learn how to use the internet safely.

Education

Levels are too high, there needs to be more accessible opportunities, we need support to go to college. We don't have enough experience. Transport links are bad.

Choice

People are afraid to make choices in case they lose what they have. We don't learn enough about choice.

Too many HIQA regulations.

Awareness

People treat you differently because you have a disability. People don't take time to understand us, how we talk. If we don't speak like them they don't listen to us.

Money

We don't have enough money to live an ordinary life.

Support

The staff tell us what to do. We can only go out when staff want to. If you live on your own you have to pay the service to bring you places because the car is owned by the service. We are stopped from going out on our own because of safety. We have limited freedom. Services don't trust us.

We live under a curfew because of poor transport links and reliance on staff or family for lifts.

Accessibility

Not enough accessible information.

Question 3 - What support do we need?

Transport

Better local buses and transport. More transport – travel passes but also a taxi scheme.

Employment

We need access to employment and job coaches. Work experience that leads to work. We need a recruitment agency for people with disabilities.

We need to get paid properly for the work we do and to be able to work enough hours without losing our DA or medical card.

Support

Flexible staffing, schedules that are set by people with intellectual disabilities themselves.

Those who aren't in services don't get help (Cork City).

Need to be helped with writing.

More confidence with speaking up for ourselves.

We need assessments of what supports people need.

It is very important that staff support us to do what WE want.

Choice

More choice.

Individualised budgets and real choice.

Development hubs as per New Directions Policy.

Community Schemes – people should not lose entitlements.

Education

Paid for courses.

Grants and supports (like SNAs) to go to college.

We need training that will give us jobs at the end, not course after course in a workshop somewhere. We want to go to the same colleges everyone else goes to, just with more supports and for jobs that we can do at the end.

Social

We want friendships and relationships and intimacy. We want our right to these things acknowledged and talked about and facilitated.

We need accessible information about sex, relationships, consent, contraception.

We need social spaces that we can get to at ordinary times, nights out.

We want support to meet our friends and families outside of service hours.

One service spoke about having a new thing that happens, where staff go to the pub once a week and we can go too if we want to. It's really good as we can meet our friends and get lifts home afterwards.

Advocacy

We need groups like the National Platform of Self Advocates where people will listen but we need them all over the country. We need proper independent groups. Everyone should be able to go to meetings.

Independence

We want more independence, to be able to get away from services altogether and live a life in the community, or for those who want it, to stay in services but to have more of a say. Services should be about us, not families.

Awareness

We want more people to understand that what we want is our rights. We just want what other people have.

Other

We need more money! Increase to the DA.
The Capacity Act needs to be fully enacted.

Question 4 - What can be improved?

Employment

The Platform can hold meetings with employers and give them an introduction to the Platform – help them develop accessible programmes for apprenticeships and training. We need paid jobs and more hours. We want training that leads to jobs.

People with disabilities should get at least the minimum wage for the work they do.

Personalised Budgets

We want to know more about personalised budgets (especially for residential services). More choice and accountability in our personal budgets and in our services. We want personalised budgets so we have a say in where we live and how we live.

Transport

We need more rural transport.

We need better transport. We can't do anything if we can't get places. All new buses and trains should be accessible.

There can be better links and access to the community.

Housing

Community housing can be better. The process is too difficult. We need to know who can support people with these processes. All new houses built by

the government or by private builders should be accessible. No houses should be allowed that aren't accessible.

Money

People don't have enough money, give them more money or help them get employment.

Don't waste money (on services that don't work).

Awareness

Changing attitudes to disability in Ireland.

More Self-Advocacy groups will make things better. Local groups of the National Platform of Self Advocates will help raise awareness for people.

Staff

Services need better training in understanding, listening, not thinking they know best, better communication, rights, personal choice.

Social

We need better support to help people live ordinary lives – having a social life. More volunteers and supports. More social networks and social clubs. More diverse experiences.

Question 5 - How should the government spend our money?

Employment

The Department of Employment Affairs and Social Protection could pay to facilitate rights training for employers as delivered by the Platform. Money to be put into employment services – employment facilitators should be trained so they can support people with different needs.

Money spent on job coaches to be trained more.

Get employers to change their attitudes.

Create more jobs for people with disabilities.

Housing

All new houses should be accessible so they can be given to anyone who needs them and so people don't have to move out if their needs become greater.

The government needs to ensure that regulation by agencies like HIQA doesn't restrict rights. Vacant houses and ghost estates should be opened up.

Create more social housing and move people in to the community.

Personalised Budgets

Introduce Personal budgets.

Make personalised budgets more accessible – have training to teach people about personalised budgets.

Give us more choice and control over our money and our services.

Transport

Money for more buses, more bus drivers, more routes around rural Ireland, especially for people who are isolated so they can live ordinary lives – go to work, go out with friends. Spend money on transport schemes.

Give money for taxis so we can have an ordinary life. Allow the travel pass to be used for taxis.

If we can't have better rural transport, we need services to have cars so we can go to work and have a social life, go to our volunteer roles or go to our place of education.

Have visual timetables at bus stops to show when the next bus will arrive.

We shouldn't have to book train journeys 3 days in advance as a wheelchair user, all stations and services nationwide should be made accessible.

Grants for transport, it's far too expensive for us.

More wheelchair spaces on transport.

The cost of parking at hospitals should be cut.

Education

Improve access to existing education – we can do Fetac level 5 but get no support to go to level 6 or go to mainstream college. We don't want to be stuck in separate workshops, let us use the same buildings and services as everyone else.

Make sure there are places for people with intellectual disabilities on ordinary apprenticeship and training schemes.

Advocacy

Fund the National Platform of Self Advocates on a permanent basis and link us in with every government department so that we have a voice everywhere that decisions about us are made.

Money should be spent on consulting with us and getting our opinion and input.

Staff

There should be disability rights training (not awareness training) for all staff in services and working for the government, people like bus drivers, social welfare office staff.

Have more flexible staff hours so we can get support to go out when we want to.

Accessibility

Make buildings accessible.

Make footpaths and roads accessible.

More Changing Places (accessible toilets with hoists and changing tables).

A grant for mobility equipment.

More parking spaces for wheelchair access.

Don't waste money on things [state services] that aren't accessible.

Social

Set up social clubs everywhere, not just in one area. They should be open all over the country and we should be able to access them wherever we want. We would like more holidays. Some people don't get holidays.

Money

Our DA was cut, we want payment back to what it was before as we can't live an ordinary life on what we get. Services and HIQA eat up our budgets.

