

NIID

NATIONAL INSTITUTE FOR INTELLECTUAL DISABILITY



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Family Voices **A survey for families of people with an intellectual disability**

Dear Parent/Caregiver,

We are a group of parents who want a better life for our sons and daughters with an intellectual disability, and also a better deal for family carers. We need you to help us by completing the enclosed survey. We are interested in your views about the things that are important to you and whether you are satisfied with how things are at present. We want the views of carers from all over Ireland and aim to get 500 carers to complete the survey. We hope you will be one of them.

This is NOT just another survey! Your views will help us to fight for positive change in the lives of people with an intellectual disability and their families. What we find out will strengthen our case when we talk to politicians, professionals and service providers.

We have joined forces with researchers from the National Institute for Intellectual Disability at Trinity College Dublin to do this survey. On the following pages are questions about different aspects of life that families across Ireland have told us are important to them. We would like you to answer all the questions but understand some may not be relevant to you, please feel free to skip these. Take as long as you need to complete the survey. We are keen to have the views of both men – fathers and brothers for example and women – mothers and sisters. As we are interested in the views of ALL family carers, more than one person from your family can complete the survey individually.

Thank you so much for sharing your opinions with us!

Frieda Finlay, Seamus Greene, Ann Lawlor, Jean Spain

Completing the survey

If you want any **help completing the survey**, or need additional copies, please phone our helpline at: 01-896-2247 or 01-896-2200 or email Darren Chadwick [chadwid@tcd.ie]. You can also download **additional copies** of the survey to print out and fill in, or fill the survey in **online** at our website [www.niidfamilyvoicessurvey.tk or www.tcd.ie/niid/news/familyvoicessurvey.php].

Instructions

Throughout the survey **N** stands for the name of your family member with an intellectual disability.

Please read and think about each statement and circle the number that represents how **IMPORTANT** this is for you. Then, read the statement again but this time rate how **SATISFIED** you are with this at present.

For example, if the statement was 'As a carer you feel supported by your GP', you might feel that it was important to feel supported by your GP and so you would circle 5 under 'How important is it that...', but you might feel that your GP is not supporting you as much as s/he should and so may circle 2 under 'How satisfied are you that...'.
'How satisfied are you that...'

How important is it that...as a carer you feel supported by your GP

Not at all 1 2 3 4 **5** Very

How satisfied are you that...as a carer you feel supported by your GP

Not at all 1 **2** 3 4 5 Very

It is important to us that you answer all the questions, but you may feel some don't apply to you or you can't give an answer to them. Please **skip** these questions by ticking the Skip Box provided:

You can change your choice of number by putting a line through the number you want to change and circling the new number:

Not at all 1 2 ~~3~~ 4 **5** Very

For some questions on page 4 of the survey, please tick all the boxes that apply to you and your family . If you need to change your answer just put a line through the box you have ticked .

Some questions refer to services. '**Services**' are residential, day, employment, mainstream and special schools, training, therapeutic, respite services and any others. Please answer questions that refer to services thinking about how you feel about the service you and your family member with intellectual disabilities are receiving or have received in the past year.

When You Have Finished

All information you give us is confidential. No one will be identified in any reports. The ratings will be grouped together to give us the overall views of all family carers.

Once you've finished it, please return the survey in the freepost envelope provided. If more than one member of your family completes the survey please return them in the same envelope. If you know of any other families who would like their views and experiences to be included in this study please give them our helpline contact details so that they can request a copy of the survey.

Family Voices:

A survey for families of people with intellectual disabilities

Throughout this survey **N** stands for the **NAME** of your family member with an intellectual disability.
 Please read and think about each statement and **circle the NUMBER** that represents how **IMPORTANT** this is for you.
 Then, read the statement again but this time **circle the NUMBER** to indicate how **SATISFIED** you are with this at present.
 Please **SKIP** statements that you feel don't apply to you or you can't give an answer to by ticking the Skip Box provided.

Statements	Skip	How important is it to you that...							How satisfied are you that...						
		Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
1. Information about disability support groups and networks is readily available to you	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
2. You have people to talk to about your worries or concerns about N	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
3. You get a chance to talk with other family carers of people with an intellectual disability	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
4. Parents get together and lobby for the needs and rights of people with disabilities	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
5. The rest of your family helps you to look after N	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
6. You have time for yourself outside of the caring role	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
7. You have made plans for when you can no longer care for N	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
8. Family carers are invited to attend training courses provided by services.	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
9. You get appointments with people in services at times that suit you	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
10. N is getting or has had a mainstream education	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
11. Schools adequately prepare N for life after school	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
12. Post secondary school educational courses are available for N so that s/he can learn new skills	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
13. Training courses are available for N so that s/he learns new skills after school	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
14. N does activities s/he enjoys throughout the day away from home	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
15. N has an ordinary paid job	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
16. N has opportunities provided to help reach his/her full potential	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
17. Services encourage the development of N	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
18. You encourage N to make his/her own decisions	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
19. N makes decisions about his/her life	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
20. N chooses the people s/he wants to live with	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
21. N decides where s/he lives	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very

Statements	Skip	How important is it to you that...							How satisfied are you that...						
		Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
22. You are given a choice of services to suit you and <i>N</i>	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
23. Services involve you in decision making around <i>N</i>	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
24. <i>N</i> is supported to have friendships outside of the family	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
25. <i>N</i> has a boyfriend/girlfriend who s/he sees regularly	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
26. <i>N</i> gets married or lives with a partner someday	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
27. Community services and facilities welcome people with an intellectual disability (e.g. shops, leisure centres, pubs, cinemas etc.)	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
28. People in your neighbourhood are understanding of <i>N</i> 's disability	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
29. <i>N</i> gets on with people in his/her community	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
30. Community services and facilities make adjustments to include people with an intellectual disability	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
31. <i>N</i> has support to be part of the community	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
32. Society treats your family the same as any other family	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
33. Public transport is available for <i>N</i> to use when s/he needs it	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
34. Information is available about different options for <i>N</i> (e.g. residential, day activities, respite, therapeutic services etc.)	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
35. <i>N</i> is well looked after and cared for in the place where s/he lives	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
36. <i>N</i> is safe from any form of abuse when s/he attends services away from home	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
37. People who work with <i>N</i> are competent	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
38. Services balance the rights and responsibilities of <i>N</i> sensibly	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
39. Services have sufficient front-line staff	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
40. Services manage turnover of staff in a well-planned and sensitive manner	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
41. Services are flexible, responding to your family's needs	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
42. Services are well co-ordinated, sharing information about <i>N</i> with each other (e.g. residential & day services, speech & language therapy, psychology, special education & schools)	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
43. Services listen to <i>N</i> and learn what is important to him/her	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
44. Services personalise the support they provide to <i>N</i>	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
45. Services and professionals adapt to what is important to <i>N</i>	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
46. Services keep you informed about what is happening in <i>N</i> 's life	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
47. Services and professionals provide information to you about <i>N</i> in a sensitive manner	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very

Statements	Skip	How important is it to you that...							How satisfied are you that...						
		Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
48. Service staff take the time to get to know you	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
49. People working in services are easy to talk to	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
50. People working in services show respect for your family's values, beliefs and culture	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
51. You can complain about services without being afraid of the consequences	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
52. N gets the clinical services s/he needs when s/he needs them (e.g. speech & language therapy, physiotherapy, OT, psychology, nursing)	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
53. N benefits from the therapy services s/he gets.	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
54. You are given guidance on managing N's challenging behaviours	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
55. N receives good health care when s/he needs it	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
56. You are able to get respite breaks when you and N need it	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
57. You trust the people who look after N when s/he is in respite care	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
58. N enjoys and benefits from respite breaks	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
59. You are provided with home help to help you to look after N	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
60. Resources can be used flexibly to meet the needs of your family	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
61. You can find Information that is easy to understand about the financial benefits you are entitled to	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
62. Information is available about the services you and N are entitled to	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
63. The government provides enough money for services for N	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
64. You know how the money services get for N is spent	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
65. Money for services for N is used appropriately	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
66. You and N are given control of the funding allocated for the things that you and N need	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
67. You get the services you are entitled to without having to fight for them	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
68. N is happy with his/her life	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very
69. You are happy with your life	<input type="checkbox"/>	Not at all	1	2	3	4	5	Very	Not at all	1	2	3	4	5	Very

What are the main things which could improve life for N and for you as a carer? (Please continue on another sheet if you wish)

About You & Your family								
Your Gender is: <input type="checkbox"/> Male <input type="checkbox"/> Female		Your Age Group is: <input type="checkbox"/> Under 35 <input type="checkbox"/> 35-49 <input type="checkbox"/> 50-64 <input type="checkbox"/> 65-79 <input type="checkbox"/> 80+		Your Nationality is: <input type="checkbox"/> Irish <input type="checkbox"/> Other European <input type="checkbox"/> Other (Please describe) _____		Have other carers in your family completed this survey as well as you? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Your Household Income is: <input type="checkbox"/> Dependent on state benefits &/or pension <input type="checkbox"/> Less than €33,000 <input type="checkbox"/> More than €33,000 <input type="checkbox"/> Skip		Your highest Level of Education completed is: <input type="checkbox"/> Left school at 15 years or earlier <input type="checkbox"/> Leaving Certificate <input type="checkbox"/> Third-Level/Postgraduate		Your Relationship to N is: <input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Brother <input type="checkbox"/> Sister <input type="checkbox"/> Foster/adoptive parents <input type="checkbox"/> Other relative (Please describe) _____ Are you a lone carer? <input type="checkbox"/> Yes <input type="checkbox"/> No Are you the main or joint-main carer? <input type="checkbox"/> Yes <input type="checkbox"/> No		Your family home's Location is: <input type="checkbox"/> Urban <input type="checkbox"/> Rural		
N's Gender is: <input type="checkbox"/> Male <input type="checkbox"/> Female		N's Home is mainly (5 days or more): <input type="checkbox"/> With you <input type="checkbox"/> In a group home in the community <input type="checkbox"/> In a residential campus/centre, hospital or institution <input type="checkbox"/> In their own house in the community (including rented) <input type="checkbox"/> Other (write in) _____		N's Day activities are: (tick all that apply) <input type="checkbox"/> Home based <input type="checkbox"/> Day/Training centre <input type="checkbox"/> Sheltered workshop <input type="checkbox"/> Regular employment <input type="checkbox"/> Supported employment <input type="checkbox"/> Mainstream School <input type="checkbox"/> Special School <input type="checkbox"/> College/University <input type="checkbox"/> Other (write in) _____ <input type="checkbox"/> No day activities		Your City/Town is: _____ Your County is: _____		
N's Support Needs, Disabilities and Health needs are: <input type="checkbox"/> Intellectual disability <input type="checkbox"/> Difficulty speaking <input type="checkbox"/> Difficulty seeing <input type="checkbox"/> Epilepsy <input type="checkbox"/> Mental Health problem <input type="checkbox"/> Physical disability <input type="checkbox"/> Difficulty hearing <input type="checkbox"/> Autism <input type="checkbox"/> Other (write in) _____ Do you consider N's Intellectual disability to be <input type="checkbox"/> Borderline/Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe/profound Do you feel N can look after his/her personal care needs?: <input type="checkbox"/> No <input type="checkbox"/> With help <input type="checkbox"/> Yes Do you feel you can leave N unsupervised?: <input type="checkbox"/> No <input type="checkbox"/> For short periods <input type="checkbox"/> Yes Can N travel independently by taxi, bus or train?: <input type="checkbox"/> No <input type="checkbox"/> Sometimes <input type="checkbox"/> Yes Is N physically aggressive to you or others?: <input type="checkbox"/> No <input type="checkbox"/> Sometimes <input type="checkbox"/> Yes				The Services N has used in the past year are... <input type="checkbox"/> GP/Doctor <input type="checkbox"/> Hospital <input type="checkbox"/> Dentist <input type="checkbox"/> Social/Leisure Clubs <input type="checkbox"/> Education/Schools <input type="checkbox"/> Day/Training centres <input type="checkbox"/> Social work <input type="checkbox"/> Community Nurse <input type="checkbox"/> Respite services/Home help <input type="checkbox"/> Occupational therapy <input type="checkbox"/> Physiotherapy <input type="checkbox"/> Speech & language therapy <input type="checkbox"/> Psychology <input type="checkbox"/> Psychiatry <input type="checkbox"/> Specialist Behavioural Support <input type="checkbox"/> Dietitian <input type="checkbox"/> Advocacy services <input type="checkbox"/> Other (write in) _____				
Your Health								
1. Overall, how would you rate your health in the past 4 weeks?			<input type="checkbox"/> Excellent	<input type="checkbox"/> Very good	<input type="checkbox"/> Good	<input type="checkbox"/> Fair	<input type="checkbox"/> Poor	<input type="checkbox"/> Very poor
2. During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)?			<input type="checkbox"/> Not at all	<input type="checkbox"/> Very little	<input type="checkbox"/> Somewhat	<input type="checkbox"/> Quite a lot	<input type="checkbox"/> Could not do physical activities	
3. During the past 4 weeks, how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health?			<input type="checkbox"/> None at all	<input type="checkbox"/> A little bit	<input type="checkbox"/> Some	<input type="checkbox"/> Quite a lot	<input type="checkbox"/> Could not do daily work	
4. How much bodily pain have you had in the past 4 weeks?			<input type="checkbox"/> None	<input type="checkbox"/> Very mild	<input type="checkbox"/> Mild	<input type="checkbox"/> Moderate	<input type="checkbox"/> Severe	<input type="checkbox"/> Very Severe
5. During the past 4 weeks, how much energy did you have?			<input type="checkbox"/> Very much	<input type="checkbox"/> Quite a lot	<input type="checkbox"/> Some	<input type="checkbox"/> A little	<input type="checkbox"/> None	
6. During the past 4 weeks, how much did your physical health or emotional problems limit your usual social activities with family or friends?			<input type="checkbox"/> Not at all	<input type="checkbox"/> Very little	<input type="checkbox"/> Somewhat	<input type="checkbox"/> Quite a lot	<input type="checkbox"/> Could not do social activities	
7. During the past 4 weeks, how much have you been bothered by emotional problems (such as feeling anxious, depressed or irritable)?			<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Quite a lot	<input type="checkbox"/> Extremely	
8. During the past 4 weeks, how much did personal or emotional problems keep you from doing your usual work, school or other daily activities?			<input type="checkbox"/> Not at all	<input type="checkbox"/> Very little	<input type="checkbox"/> Somewhat	<input type="checkbox"/> Quite a lot	<input type="checkbox"/> Could not do daily activities	

Any Other Information – Please use this space to write in any other information, thoughts or suggestions you have about how things could be improved