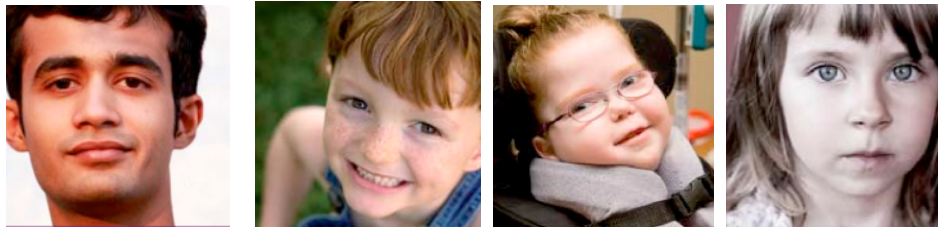


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## Research Briefing:

**“I want to be treated the same as my brothers!”**

### **Views of Quality Of Life from Children and Young People who are Disabled and/or Living with Long Term Conditions**



#### **About the Research**

For Scotland's Disabled Children Liaison Project (fSDC) and Long Term Conditions Alliance Scotland (LTCAS) commissioned Scotinform Ltd. to conduct a survey of children and young people (aged 5-18) who are disabled or living with long term conditions. The research aimed to explore the lives, attitudes and experiences of children and young people and to determine how far and in what ways they are supported to enjoy a good quality of life.

A total of 91 questionnaires, from young people aged 5 to 18, were returned.

We recognise that the survey method is not accessible to all children and young people who are disabled or living with long-term conditions. However, it did allow us to draw on comparison data from both the European KIDSCREEN survey of 20,000 young people and the *Being Young in Scotland* study with a sample of over 2000. This has allowed us to highlight those areas where disabled children and young people and those with long term conditions have similar views and experiences to their peers and those where there appear to be differences.

Many of our respondents offered comments which give telling insights into their experiences, bringing alive the quantitative data.

## **Key Issues Emerging from the Research**

### ***Friends, social life and being included***

Confirming the findings of other research, this study shows that many children and young people who are disabled and/or live with long term conditions experience significant levels of social exclusion. Many reported having few friends and needing more support to access leisure opportunities.

- Just under a third of respondents had never or seldom spent time with friends in the past week.
- A quarter had never or seldom had fun with their friends.

*“I would like help to socialise in clubs after school but there is not the support to enable me to do this”*

*“No one ever wants to go out with me.”*

*“I need an adult with me as I need support. Not always good to go with a parent - can be embarrassing but I don't know how to get to the places. I would get lost or hurt.”*

*“Being a wheelchair user makes things difficult. Lots of things cannot be spontaneous, lots of plans and forward thinking has to be done.”*

*“[I would like to] have friends and go out at night [but I] don't have friends”*

Disabled children and young people have a right to ‘special care and support... so that they can live full and independent lives’ (UNCRC Article 23) as well as a right to participate in recreational activities (UNCRC Article 31).

*Key message – There is a need to develop a range of supports to enable children and young people develop and maintain friendships with peers, disabled and non-disabled, and enjoy more leisure opportunities. This could include befriending, buddy schemes and capacity building in mainstream social clubs and recreational organisations.*

## ***Being listened to***

A relatively high proportion (40%) of children and young people said that people at school 'always' listened to their views. However almost half (49%) said their views were only 'sometimes' listened to.

While this indicates scope for improvement within schools, the bigger issue was found to be in non-school settings. Many respondents perceived health and social care professionals as pretending to listen, or being too busy to listen.

*“Because I can't talk, some people at school just made up what they thought I was saying. A lot of people just ignored me like some of the therapists and nurses.”*

*“It feels like doctors and nurses are too busy to listen.”*

*“It is good when someone takes the time to listen but time is always a problem.”*

*“I hardly ever get listened to by doctors or anyone (with one or two exceptions).”*

The United Nations Convention on the Rights of the Child (UNCRC) gives children and young people the right to be heard. This principle is at the heart of key Scottish policies including Getting it Right for Every Child, the Additional Support for Learning Act and “Gairm Yersel” The Self Management Strategy for Long Term Conditions in Scotland.

*Key message – Action is needed to significantly improve the extent to which children and young people are listened to by health and social care professionals. This should include communication skills as a priority for all professionals working with children and young people with communication or learning impairments.*

## ***Getting help at school***

The research revealed issues with the way medical and personal care needs are met at school with a few respondents describing situations where their well-being and dignity appear to be seriously compromised.

Nearly a third of pupils needed help with personal care at school: classroom assistants and parents were the main people who provided help with eating or going to the toilet.

*“I soil myself at school. I tell my teacher, she tells the office. They phone my Mummy. My Mummy drives 15 mins to school and changes me. Then I go back to class. My school is sympathetic but say they are not allowed to change me when I soil myself.”*

Of the eight respondents who said they needed help taking medicines, four said they could *not* do so when they want to.

Several respondents offered additional comments on the type of support they would like at school but do not currently get. This included more help in classes, receiving the same level of education as children and young people who are not disabled/living with long term conditions, and support to participate in extra-curricular activities.

*Key message – There is an urgent need for local authority education departments and schools, in conjunction with NHS Boards, to review policy and practice around supporting pupils’ medical and personal care needs at school to ensure these are met effectively and in ways which respect the child/young person’s dignity and privacy.*

## ***Emotional wellbeing***

43% of children and young people described their life in the past week as 'very' or 'extremely' enjoyable and a similar percentage said they had 'very often' or 'always' been in a good mood and had fun. However, despite these relatively positive findings, a significant proportion of respondents were likely to have felt sad, lonely and felt so bad that they did not want to do anything.

- 27% felt sad 'quite' or 'very' often
- 26% felt lonely 'quite often', 'very often' or 'always'
- 22% were not happy with the way they are
- 20% felt so bad they didn't want to do anything

The results from *Being Young in Scotland* show that disabled children were more likely to feel sad than non-disabled children. Comparisons with KIDSCREEN results confirmed that respondents to our survey had lower scores for psychological well-being than the European average.

## ***Future aspirations***

It is worrying that a significant proportion of children and young people have low expectations of the academic qualifications they will achieve or the type of jobs they might secure.

Just over a third of pupils hoped to leave school with Highers/Advanced Highers, compared with nearly two thirds of respondents to the Being Young in Scotland Survey.

*Key message – Schools must encourage children and young people to reach their full academic potential regardless of disability or condition and, wherever possible, study for a similar range and level of qualifications as their peers. There is a need to improve the careers advice available to children and young people who are disabled or have long term conditions.*

## Conclusion

Perhaps the clearest message to come out of the study is that disabled children and young people and those with long term conditions want access to the same opportunities and experiences as their peers, with appropriate support provided as required.

That message, and the other findings of this research, have been fed into the Scottish Government's National Review of Services to Disabled Children. The research will also help to inform LTCAS' work to influence services supporting people living with long term conditions, including implementation of the Healthcare Quality Strategy for NHS Scotland.

It is hoped that public, voluntary and independent organisations working with children and young people throughout Scotland will act on the findings of this report.

You can download the full report at:

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

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

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For Scotland's Disabled Children Liaison Project  
and  
Long Term Conditions Alliance Scotland (LTCAS)

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