

# “I may have CF, but it does not have me”

## Independent Living and Cystic Fibrosis

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### Introduction

*“Independent living is the daily demonstration of human rights-based disability policies....this includes the opportunity to make real choices and decisions regarding where to live, with whom to live and how to live”<sup>1</sup>*

Ireland has the highest incidence of Cystic Fibrosis (CF) worldwide, an inherited life-long disease that primarily affects the lungs and digestive system. People with CF (PWCF) experience “exacerbations” of their condition. These exacerbations interrupt education, training and employment. The disease, and it’s associated care, are major barriers to Independent Living for PWCF.

In 1998 and 2017, Cystic Fibrosis Ireland (CFI) undertook surveys of adults with CF in Ireland to identify the key challenges and barriers to Independent Living and to gain a snapshot of the perspectives and ambitions of the adults CF community<sup>2</sup>.

**Table 1.1 Comparable results from the 1998 and 2017 surveys**

Comparable data from the 1998 and 2017 surveys	1998 Independent Living Survey (n=83 respondents)	2017 Independent Living survey (n=145 respondents)
Gender	48% Female 48% male 4% did not say	56% Female, 42% Male, 2% did not say
Age	Age range 16-43 Aged 16-20 55% Aged 21-30 37% Aged 31-40 6% Aged 41-50 1%	Age range 16-55 Aged 16-20 10% Aged 21-30 1% Aged 31-40 38% Aged 41-50 15% Aged 51 or older 2%
Marital Status	8% Married 87% Single 5% Unknown	27% Married 1% Separated/ Divorced 32% In a relationship 39% Single 1% Other
Education	38% Completed or in third level education	49% completed a third level NFQ level 6 or higher
Employment: Tell your employer about your CF?	Tell 44% Don't tell 56% *Based on actual experience	Tell 92% Don't Tell 8% *Based on actual or hypothetical experience
Housing	74% live with parents in parent's house	43% live with parents in parent's house 9% on social housing waiting list 9.6% living in local authority housing
Factors preventing living in own home	52% financial restrictions	63% financial restrictions
Transport	Majority relied on public transport 18% own car	19% of all journeys public transport 84% own car

### Methodology

- 1998 survey, postal questionnaire with follow-up interviews
- 2017 survey, more comprehensive but compatible with 1998, on line via SurveyMonkey.
- Investigated key factors that make independent living possible

### Results

The comparative results can be seen in Table 1.1

### Conclusion

Adults with CF are living longer and healthier lives compared with 20 years ago.

Living arrangements for PWCF have changed dramatically in recent years. There are additional barriers preventing PWCF from accessing adequate housing

Third level education attainment has increased significantly. However, CF continues to impact on ability to perform and causes college drop out

Many PWCF are now in a diverse range of full-time and part-time jobs and employers are more understanding than two decades ago.

There is increased car ownership, mobility and travel abroad.

Many PWCF are impeded or deterred from starting a family because of the very high cost of IVF and the lack of state supports.

In 1998, the very poor extent of CF services in Ireland significantly reduced the reality and ambition of PWCF for independent living. The improvements evident since 1998 have greatly contributed to the increased reality and ambition for independent living in Ireland.

### References

- <sup>1</sup>European Network on Independent Living. [www.enil.eu](http://www.enil.eu).  
<sup>2</sup>Full report available: <https://www.cfireland.ie/>