

Parental Journey Report - In Brief

Prepared By Louise Clarke October 2013

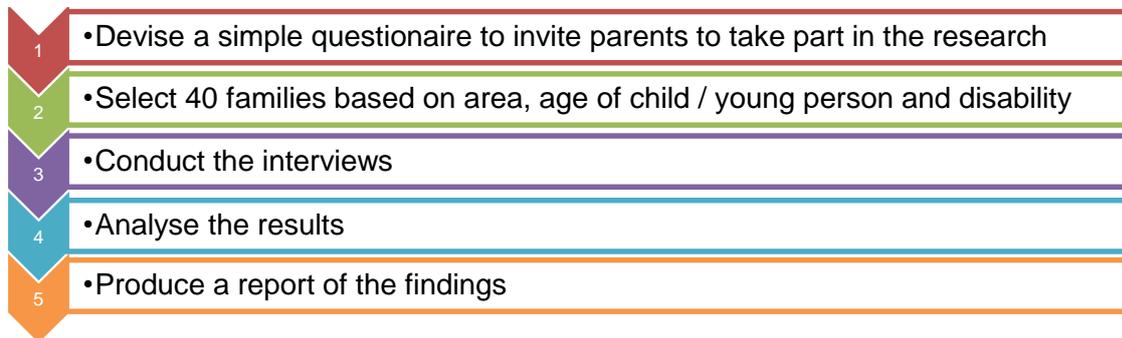


Introduction

The idea for this research project came from a representative of The Hampshire Parent / Carer Network and was developed, co-ordinated and resourced by Parent Voice. Parents felt that the research would provide a good basis on which to develop the Local Offer as it would provide a cross functional view of the provision of information. It would also provide a baseline to measure the effectiveness of the Local Offer in the future.

The main aim of this research is to understand how parents have been able to find information at different stages of their child's development (e.g. diagnosis, starting school and transition), what works well and what information is particularly hard to find. The research also aims to understand the emotional impact information can have on a family and whether good quality, timely and accurate information can help.

Methodology



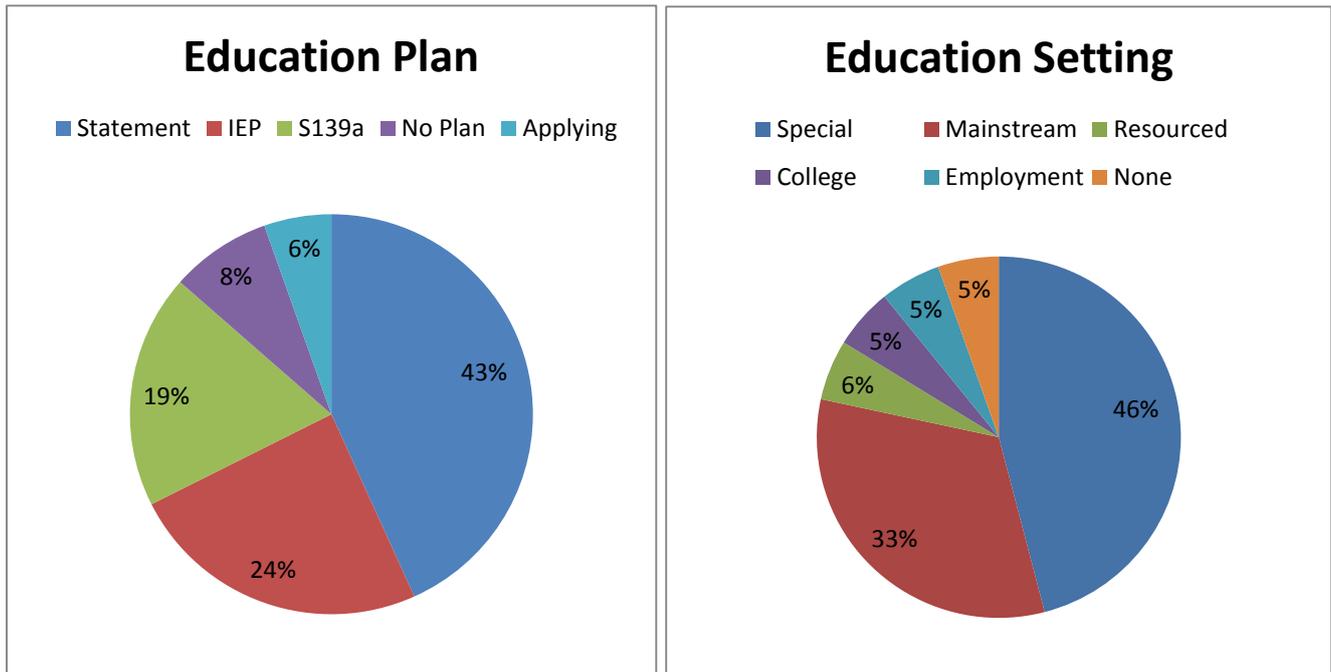
Who participated in the research?

31 families across 11 Hampshire Districts. Hart and Rushmoor 5, East Hants 6, Basingstoke 3, Test Valley 3, Havant 4, Eastleigh and Winchester 3, Fareham and Gosport 3, New Forest 4

37 children and young people aged between 0-25 years. Three children aged 0-4 years, 14 children aged 5-10 years, nine children aged 11-15, six young people aged 16 – 19 years, five young people aged 20-25.

Disabilities of the children and young people include, Autistic Spectrum Conditions, Global Developmental Delay, Cerebral Palsy, Down Syndrome, Rare genetic disorders, Profound and Multiple Learning Difficulties, Heart Condition, Spina bifida, Type 1 diabetes, Hemiplegia, Microcephely and Angelman Syndrome.

The children and young people had the following plans in place.



Key Findings

What parents said works well:

- Having a single point of contact or someone to talk things through with
- Parent friendly websites, leaflets and printed booklets
- Having options and choices - being involved in the decision making
- Effective signposting – particularly when not eligible for a service and at the point of diagnosis
- Having information prior to appointments knowing who's who, what they do and what they can expect
- Being listened to
- Professionals working together
- Information from other parents and support groups
- Independent Assessments Therapies and Support

When things work well, families feel involved, they feel that they matter, they feel supported, kept in the loop, this in turn reduces stress, helps families feel more in control and empowered.

Some of the challenges

- There is a clear message that parents feel 'left to their own devices'
- They find a lot of information by accident and find a lot of information too late
- They feel that some information is 'hidden' (particularly around statements and Core Assessments).
- That they have to learn to be pushy and continually 'fight for services'
- That professionals assume that parents 'know everything' and don't signpost.
- That professionals are listened to over and above parents
- Cross border issues (who is responsible and who pays)
- Misinformation, 'jargon' and not following processes

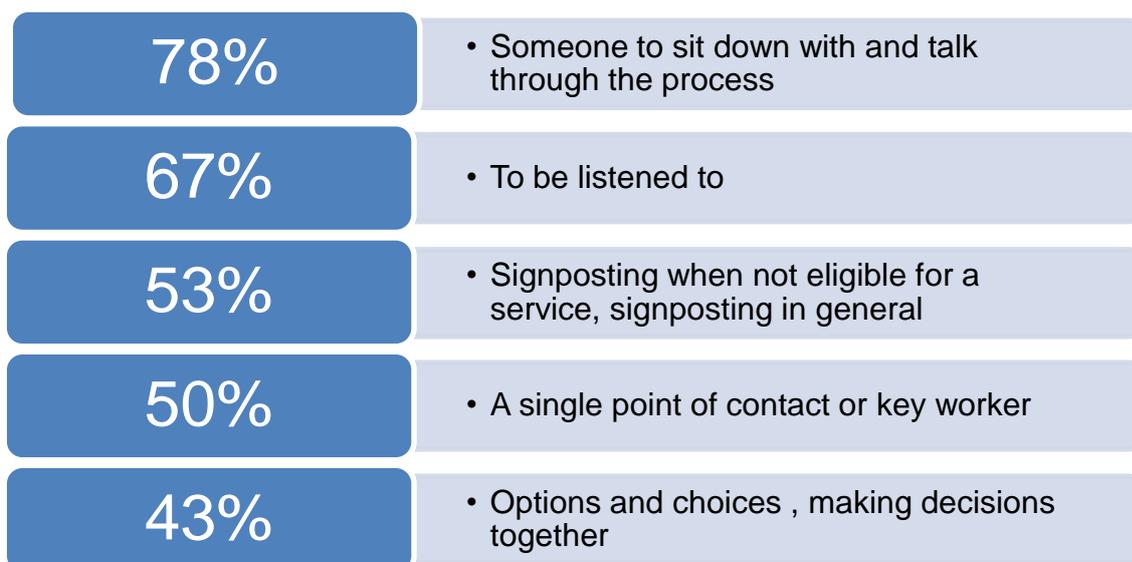
When faced with some of these challenges, parents feel angry, isolated, 'farmed out', let down, inadequate, isolated, overwhelmed and lost. They feel a great deal of guilt and confusion which has a direct impact on their ability to 'cope' and on their confidence. Parents said that they take legal action, or become difficult because there is no other option. Many feel that conflict can be avoided if there is greater transparency about how decisions are made and if sign posting is more effective.

What information is particularly difficult to find?

- Information pre-diagnosis or at the point of diagnosis
- Information about eligibility criteria and the referral process
- Information about waiting times
- How decisions are made (particularly in relation to statements and Social Care assessments)
- Information about Disability Living Allowance and Carers Allowance
- Incontinence, wheelchairs, SEN Dentists and hairdressers
- Information around transition and implications of a child reaching adulthood

Although some of this information is universally available, parents are not advised that they are eligible and therefore don't look for the information. Parents also commented that government and Local Authority websites are often complex and written in a way that is difficult to absorb and understand.

These are the Top Five things that parents said that they would have liked



Other suggestions of what parents 'would like'

- Greater support and training for professionals in schools, health and government bodies (e.g. Job Centre) about Disability
- A timeline of what a child might need in the future, what do parents need to start preparing for? When?
- An improved system for transition and accessing Further Education
- Transparency about waiting times, expectations and decision making
- Advice on preparing for meetings and preparing to go into hospital
- A who's who of professionals
- A user friendly website

Recommendations and Conclusions

The Local Offer will help to address some of the issues highlighted and there are some good suggestions that can easily be incorporated, however, it is clear that a website will not be sufficient to meet parent needs. It is important therefore that the Local Offer is supported by 'real people' who can act as a single point of contact for information and can listen to families and talk them through the process. If professionals engage with the Local Offer then this will improve signposting and families will not find information by accident or too late. Engagement across all sectors will be the key to its success.

Further recommendations can be found in the full Parental Journey Report. Available at www.hampshirelocaloffer.info