

## **‘Adults on Paper’: Caring for Children as ‘Adults’, Ethnicity and Cultural Stigma**

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### **Introduction and Overview**

Over the past year Saima and Asma have been leading research and film-making to describe the challenges carers face supporting their ‘children’ who are now becoming adults and have additional support and complex needs. All of the ‘children’ are neurodivergent. Saima and Asma have drawn on their own living experience and brought together the voices and stories of other mothers and carers they have met also on their journey. They also explore how this subject intersects with their ethnicity and the cultural stigma faced.

### **Key Facts and Wider Research**

- There were 241,639 pupils (34.2% of all pupils) with an additional support need (ASN) recorded in 2022 (Scottish Government, 2022).
- 1 in 100 people in Scotland are autistic but it’s often misunderstood (Different Minds).
- There are actually estimated to be around 700,000-800,000 unpaid carers in Scotland. Many have never been in touch with services and are not accessing support (Care Information Scotland, undated).
- The transition from children to adult services has been noted in other research to be a difficult process for young people and their families (Hall, 2019).
- Where mothers take care of dependent adult children, they de-prioritise their own needs, grieve for the lives they thought they would have had and feel tremendous guilt when they have to think about or deal with their own needs (Smith, 2022).

### **Key Findings: The issues**

- *‘The mental load of caring is huge.’* All carers interviewed have physical health conditions that are linked to the stress they have endured. They feel like they have lost their identity and are misunderstood and judged by wider society as mothers, as their children with an ASN struggle to manage their challenging behaviour.
- Women from ethnic minority backgrounds can feel especially isolated as they do not have family that live close and there is a lot of cultural stigma around disability.
- Getting a diagnosis took many years and it felt like no one was listening.
- Self-directed support is a challenge and sometimes impossible to access.
- Currently when people with an ASN reach the age of 16, they are no longer entitled to support and so for carers this again relies solely on them.
- Wider services do not know what support is available for families who experience these issues.
- It was felt that support is only really given when people have reached crisis point.

### **Key Findings: The Solutions Proposed**

- There is a call to professionals to listen to families earlier, so they do not reach crisis point.
- Families would like information about what is available to be more easily accessible. For example, for GPs and social work services to know where they can direct people for support.
- The parents called for quiet spaces in schools, colleges and throughout the city for people with an ASN to have space to regulate their emotions.
- The main and most effective support carers have found is the chance to meet with other carers who are experiencing the same difficulties so they can help each other and address isolation.
- Carers said that without services such as VOCAL, BEMAS Action Group, they were not sure that they would have had the strength to carry on, and wanted these services to continue.
- Carers propose having a centre where families who have children with additional support needs can attend, to get support and to support one another.