Lifespan Development in Autism

A grounded theory study of the life experiences since leaving school in a cohort of adults in middle life

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Understanding Felix
What happens to people with autism in middle age and beyond?
Literature review

(1) Need for research on age-related change not age-related difference
   Importance of retrospective detail

(2) Need for experiential research
   Importance of hearing individual’s voices
Methodology

Sample: Families and caregivers of 7 former students
Retrospective study
Grounded theory – no pre-existing assumptions
7 Semi-structured interviews
Analysis

Initial coding → Focused coding → Categorising → Theoretical category development → Reaching theoretical sufficiency
Parents as Champions

“every single thing that he has done, every change of direction, every kind of service has been initiated by ourselves”

- Participant 2
  Father of 26 yr old former student
Continuing Development

“she is continuing to surprise us with her abilities”  
“still able to develop new skills”  
- Participant 3  
Father of 41 yr old former student

“I am proud of her ability to cope with complex situations”  
- Participant 1  
Mother of 31 yr old former student

“Now he’s older, he’s just a big gentleman”  
- Participant 10  
Mother of 44 yr old former student
Individualised development

Adults with autism fixed their own markers of change
Recognising a valued self
Realising one’s own individual goals and needs

Artist
31 yrs

Baker
26 yrs

Choir singer
41 yrs

Enjoys walks
43 yrs

Artist
31 yrs

Music-lover
50 yrs

Gardener
44 yrs
“Will I still go to my Garden centre* when Mum is not here?”

- Former student 7

*Name has been changed
What does the future look like?

Further research into lifespan development

Age-appropriate services

Continuing opportunities for development

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*All identifying information and names have been changed to protect the anonymity of the participants


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**Summary of Quality of Life Research Findings**

[http://research.ncl.ac.uk/adultautismspectrum](http://research.ncl.ac.uk/adultautismspectrum)


