

A high-angle, blurred photograph of a crowd of people walking on a light-colored, paved surface. The motion blur gives a sense of a busy, crowded environment. The people are dressed in casual to semi-formal attire, and their movement is captured in various directions across the frame.

Perspectives and transition experiences of adolescents and young adults with disabilities

'Better Mental Health for People with Intellectual Disability'

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INSIDE | INTEGRATIVE RESEARCH UNIT
ON SOCIAL AND INDIVIDUAL
DEVELOPMENT

Institute for Research on Generations and Family:
Youth Research

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Structure of the presentation

1. Context of the study
2. Data basis and methodological approach
3. Results
4. Conclusions

1. Context of the study

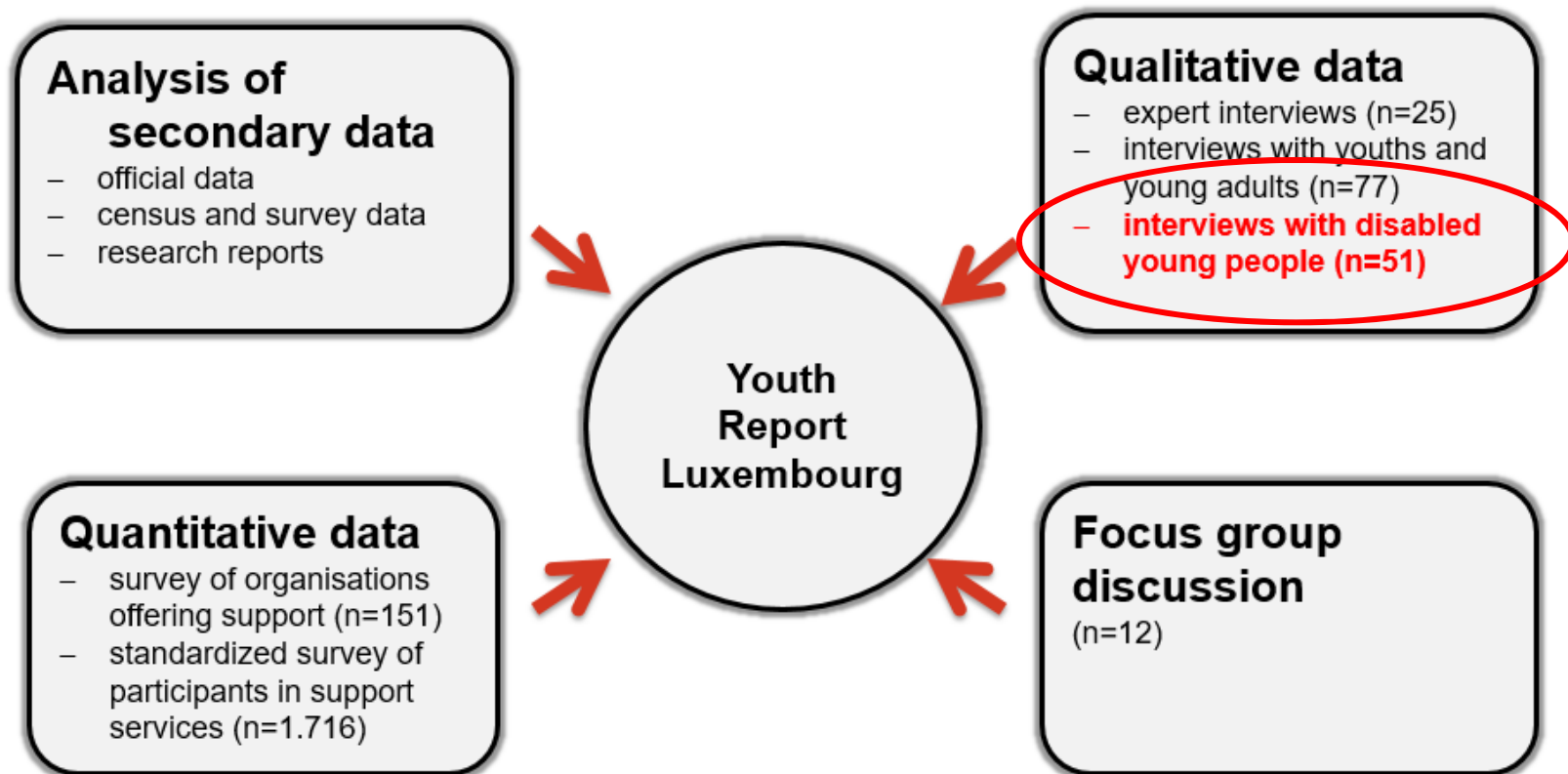
Context of the study



- Youth Report Luxembourg 2015
- Main subject: Transitions from youth to adulthood
- Expertise: Transition of young people with disabilities

Context of the study

Underlying data and scientific methods of the Youth Report 2015:



2. Data basis and methodological approach

Data basis and methodological approach

Research questions:

- What are the **ideas and wishes** of adolescents and young adults with a disability **about being and becoming an adult**?
- How do they **accomplish** the transition to adulthood and what are the **challenges and difficulties** they face?
- How do young people with a disability **experience their impairments** and how do they **cope** with them?

→ subjective perspectives of persons concerned

Data basis and methodological approach

- **Research method:** problem-centered semi-structured guided interviews (open, however based on a fixed sequence of questions) (Witzel 2000)
- **Sample size:** 51 youths and young adults in Luxembourg aged between 15 and 35 years with one or more of the following types of impairment:
 - physical disability
 - mental/intellectual disability
 - psychological disability
 - autism spectrum disorders (ASD)
- **Analytical strategy:** content analysis (Mayring 2010)

Data basis and methodological approach

- **Recruiting of the interview partners:** «gatekeeper method» (via professionals in organisations for people with disabilities)
 - **Methodological particularities:**
 - Communication difficulties
 - Short attention span
 - Impulse control and mood swings
 - Using a support person
- Not all interviews could be used at the end

3. Results

- **School-to-work transition**
- **Transition to independent living**
- **Private transitions: partnership and parenthood**
- **Coping strategies**

School-to-work transition

Mostly negative experiences during school

- Learning difficulties

“At one point it was impossible for me to learn, I had to stop, I wasn’t able to do any assessments, I wasn’t able to concentrate.” (Bernard, 19 years old)

- Low self-confidence due to low level of qualification

- Experiences of exclusion

“[Then I was] excluded by this teacher. (...) During the time the others were taking their exams, I went there [out of the classroom], I was sent there. [After] I could come back to the classroom. During the time where the others were taught something, I could come back. [However I] could draw then, or do something similar. I couldn’t do something real.” (Pascal, 26 years old)

School-to-work transition

Mostly negative experiences during school

- Experiences of bullying and exclusion by school mates

“There I had a lot of problems with mobbing because the majority of people does not know anything about Asperger. And the teacher thought, I don’t know, that I might be somehow disabled, or that everything was my own fault or that kind of blabla.” (Christophe, 22 years old)

“Mobbing, bullying, a bit of everything. There was a time where I got a huge depression, I didn’t get out of my bed. I was afraid of going to school. I was truly afraid.” (Gaby, 27 year old)

“...that we are stupid, that we are disabled and that we are not capable to do anything, I’ve heard this many times. (...) Yes, in my village, [from people] from other schools. (...) Then I feel sad and I simply go away.” (Christelle, 17 years old)

School-to-work transition

Limited opportunities in the first labour market

- Only one in seven has a job on the regular labour market
- «regular careers» are rare, most of them work in special institutions

“I immediately entered the ATP, one of the reasons was that I wanted to strengthen myself, because actually I was not that well off, so that I could exercise myself in working eight hours. (...) It does have some advantages, but (...) you are so labelled, I really don’t like that at all.” (Bernard, 19 years old)

“Then I started working here immediately, because outside, I cannot compete on the first labour market.” (Romain, 25 years old)

“...because I didn’t have any other choice, for after school...” (Pascale, 18-21 years old)

Transition to independent living

Desire for autonomy and independance from parents on the one hand...

- Strong desire for autonomy, freedom and independance

*“I want to leave from there now: it simply means more freedom, more independence ... (...) and I don’t want to squat much longer at my parents’ place.”
(Bernard, 19 years old)*

- Detachment from parents considered as a necessary step towards adulthood

“[I] would love to become more autonomous, because this is my big wish, also because then you can grow up as an adult and learn more in life.” (Yannick, 32 years old)

Transition to independent living

...yet on the other hand dependent on support and help

- Process of detachment is difficult due to dependency on parents

“[I am] a bit afraid of the idea of living alone.” (Béa, 30 years old)

“It’s normal, I mean somebody was looking after me my whole life... Yes, it is due to the illness, but I wouldn’t like to be alone, I mean not yet, not at this specific moment in time, no.” (Elise, 26 years old)

- Overprotecting parents preventing autonomy

“My mum doesn’t let me go (...). I would like to have more freedom, managing myself you know?” (Elise, 26 years old)

“[It is disturbing me, that she] is inquiring the whole time when I am doing something ... where are you going, what are you doing... I sometimes feel suffocated.” (Béa, 30 years old)

Transition to independent living

Housing situation of the interviewed persons

- Nearly all the interviewees would like to live independently

“Yes of course, at some point one has to move out, it’s clear that one cannot live forever at mummy’s place, with one’s parents.” (Oliver, 20 years old)
- Majority still lives with their parents though – for different reasons

“Oh no. No, not living alone. (...) I’m a single child, therefore I’m still living there. It’s clear, I can’t leave mummy alone”. (Jean-Paul, 25 years old)

“At the moment the situation at home is convenient, maybe until there are more [financial] reserves, so that I am more secured. But, as said, I’m still happy at home.” (Franck, 27 years old)
- Compromise solution for some: assisted living (sheltered housing)

Private transitions: partnership and parenthood

Perspectives on partnership

- Ideas, wishes and dreams with regard to partnership and intimacy do not differ from those of their able-bodied peers
- Realisation, though, is considerably more difficult
- Impairments make search for partners more difficult

“But when women know that you are sick, or that you’ve got a Psychosis or that you are schizophrenic, then they are scared, and say he’s a freak, he’s crazy. People won’t tell you that, but... I know exactly that this is what they are thinking. I am afraid to start dating her, this will not go well for long...” (Guy, 25 years old)

Private transitions: partnership and parenthood

Perceptions of parenthood and starting a family

- Responsible and realistic view on parenthood

“I can have kids, however I don’t want to take that risk, I wouldn’t even wish my greatest enemy to go through what I had gone through, what I had to go through during the last years.” (Martine, 29 years old)

“I know how difficult it was, considering solely my school career, with mobbing and such things, I wouldn’t like do that to a another kid.” (Robert, 30 years old)

“I mean having a child would be a bit too much at this point of time.” (Chantal, 22 years old)

“I’ve asked myself a lot of question since I’ve received my diagnosis, and told myself that as long as I have some difficulties with myself, then it would be difficult to be a good mum.” (Béa, 30 years old)

Coping strategies

Dealing with their impairments

- Do not perceive themselves as disabled person, but as a person with a disability in certain specific situations

“To me it seems very negative and labeling, if you say I am disabled.” (Christophe, 22 years old)

“The illness is part of me, yes. I mean, I don’t define myself through my illness, but it is however a part of me.” (Elise, 26 years old)

“I’m maybe sitting in a wheelchair, but I don’t feel like that, as you say, disabled. Because, look, I can... I am happy, I can think, I can talk, I can take initiatives.” (Nicolas, 29 years old)

Coping strategies

Dealing with their impairments

- Found a way to deal with their impairments

“Most are doing the same as I what I’m doing: They try to live as if there would be nothing wrong, as if they wouldn’t have anything. I mean no retardation or similar. That works not always, but often.” (Chantal, 22 years old)

“I’ve simply learned to deal with it, and that there are things that I cannot do, and then I try to find another solution, you know?” (Elise, 26 years old)

“The [illness] is rather in the background. (...) It’s simply, I know that I have it, but I try to live as normal as possible in society.” (Robert, 30 years old)

Coping strategies

Dealing with stigmatisation and exclusion

- Try to become immune to stigmatisation and boost their own feeling of self-worth

“Maybe earlier I was thinking that because I’m sick, I cannot deal with certain things so well. Maybe that is still the case, the others might be more capable to do it, because they are not sick, but it’s not [anymore] the case that I’m subordinating myself and thinking that the others are better than me. (...) I am as good as the others, even if I’m sick.” (Bernhard, 19 years old)

“When somebody stares at me, than I think, this actually shouldn't bother me, you know. That goes in one ear, and out the other.” (Pit, 36 years old)

→ Reconstructing themselves and redefining social norms

Conclusions

Conclusions

- **Same ideas and aspirations** about being an adult
- Transition to adulthood presents a disproportionately **tough challenge** compared with their able-bodied peers: same developmental tasks, but **achieving them is more difficult** because of their physical, mental or psychiatric impairment
- Dealing with experiences of exclusion and stigmatisation as an **additional developmental task**
- **Desire and determination** to shape their own lives for the better
- *“ability to surpass ,objective‘ conditions, reconstructing them and creating new meanings”* (Zittoun et al., 2013, p. 351)



**Thank you for your
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