Supported Education: community participation for people with psychiatric disabilities

Overview

- Welcome and Introduction of Supported Ed.
- What hinders and what helps?
- Self-disclosure
- Supported Education in Sweden
- Questions & discussion

Introduction of Supported Education

A journey from despair...
...to a life filled with purpose

Research project 'Recovery After an Initial Schizophrenia Episode (RAISE)
Mission of SEd
To help (young) people with psychiatric disabilities to choose, get and keep regular education

SEd: the bridge between psychiatry and education

Psychiatry  SEd  Education
Patient ↔ Client/consumer ↔ Citizen ↔ Learning ↔ Student

What hinders and what helps?

Lies Korevaar, PhD
Jacomijn Hofstra, PhD
Background

- European ImpulSE project (2013-2015)
  - Aim: Development of a Toolkit Supported Education
  - Partner countries: Norway, Portugal, Czech Republic and the Netherlands

- Important question: ‘What hinders and what helps students with psychiatric disabilities when choosing, getting and keeping a study?’

Method

- Literature review:
  - Both peer reviewed and ‘gray’ publications
  - 30 questionnaires from experts in supporting students with psychiatric disabilities (both educational and mental health professionals (NO 10; PO 3; CZ 4; NL 13)
  - 27 interviews with students with psychiatric disabilities (focus groups) (NO 6; PO 5; CZ 7; NL 6)
    - 13 male, 14 female.
    - Age between 17-60.
    - Diagnoses e.g.: depression, PTSD, schizophrenia, anxiety disorder).

Method: Analysis of literature/questionnaires

- For each question
  - the findings/answers were put together in one document
  - Findings/ answers with more or less the same content were given a color. E.g.: all answers about ‘lack of self-esteem’ were coded in red. This way, it was easier to identify categories or ‘factors’ in the answers.
  - The experts gave feedback on the results/conclusions
Results

- Little SEd literature available in the four countries

Three categories of barriers

- Personal barriers
- Barriers related to the educational environment
- Barriers related to the social environment

<table>
<thead>
<tr>
<th>Barriers when Choosing (mentioned in at least 2 of the 4 countries)</th>
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<tbody>
<tr>
<td><strong>Personal barriers</strong></td>
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<td>Fear of being</td>
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<td>application procedure</td>
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<td>communication between</td>
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<td>them</td>
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<td>Lack of knowledge</td>
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<td>people with</td>
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<td>psychiatric</td>
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<td><strong>Keep</strong></td>
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<td>Direct consequences</td>
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<td>Difficulties with</td>
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<td>executive functioning</td>
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<td>skills</td>
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<td>Lack of self-esteem</td>
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<td>Dilemma of</td>
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<td>disclosure</td>
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<td>Feeling of</td>
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<td>stigmatization</td>
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<tr>
<th>Barriers when keeping</th>
<th><strong>Personal barriers</strong></th>
<th><strong>Barriers in educational environment</strong></th>
<th><strong>Barriers in social environment</strong></th>
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<td><strong>Keep</strong></td>
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<td>Lack of support</td>
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<td>Inflexible structure</td>
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<td>from fellow students</td>
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<td>Stigmatization/discrimin ation by fellow-students</td>
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<td>Stigmatization/discrimin ation by teachers</td>
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<td>Little or no support</td>
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<td>from family and friends</td>
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<td>Little or no support</td>
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<td>from mental health professionals</td>
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Conclusion

- Frequently mentioned barriers:
  - Fear of failure
  - Stigmatization
  - Problems related to illness or medication
  - Lack of support

- More similarities than differences between the countries
  - Portugal: lack of financial means
  - The Netherlands: lack of information about support services

What helps?

Choose
- Clear information about available support services at school
- A decision making course
- Support from social environment

Get
- Support from mental health professional with the application procedure and with finding special arrangements
- Information about what to do, where to find information and where to go with questions

Keep
- Frequent personal contact about study related issues with SEd professional
- Flexible school system
- Peer support group
- Support with disclosing ones psychiatric background

Toolkit

Toolkit is freely available at www.supportededucation.eu

The toolkit is available in English, Dutch, Norwegian, Czech, Portuguese and Swedish
‘To tell or not to tell’
Disclosing a psychiatric disability in an educational setting

Jacomijn Hofstra, PhD
Lies Korevaar, PhD

Inez
Inez is 23 years old and first year University student. At the age of 19 Inez became very depressed. She attempted suicide and has been admitted to a Mental Hospital for some time. She has been in Day Treatment at the same Mental Health organization for the past two years. The last year Inez has been doing very well and she went back to study Economics again (at a different University). In an introductory meeting with the lecturer and other students, the lecturer asks Inez: “Inez, what have you done before?” Inez is surprised by the question and doesn’t know what to say.

Research on Disclosure
People who receive support with making a decision whether to disclose or not (in a work setting):
• experience less stigma stress (Rusch et al., 2006);
• experience less decisional conflicts, and
• more often keep their paid jobs (Henderson et al., 2013)

Research on Disclosure

Disclosure

“Disclosing your psychiatric disability” means that you tell someone about your past/current psychiatric condition

To decide whether to tell about one's psychiatric disability or not, one could consider the following aspects:
5 aspects of the skill Disclosing

- Whether
- How
- Who
- When
- What

Disclosing your psychiatric background

<table>
<thead>
<tr>
<th>To tell or not to tell?</th>
<th>a. What are the benefits of disclosing?</th>
<th>b. What are the disadvantages of disclosing?</th>
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</thead>
<tbody>
<tr>
<td>Understanding/acceptance classmates</td>
<td>Possibility of discrimination</td>
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<tr>
<td>Access to support/adjustments</td>
<td>Misunderstanding of disability's impact</td>
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<tr>
<td>More support/care teaching staff</td>
<td>Possibility of being singled out in class</td>
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</tbody>
</table>

c. Compare the benefits and the disadvantages. Which are most important to you? Rank the benefits and disadvantages of disclosing from most important to least important.

d. Did you make a choice? Do you tell or not?

Feasibility study: Research questions

1. Does the degree to which the students are concerned about disclosing or not decline after using the disclosure tool?

2. Does the level of experienced decisional conflict (uncertainty about a course of action) decline after using the disclosure tool?

3. What are the experiences of the students with the Disclosure-tool?

Method

Sample
- T1: 14 students with psychiatric disabilities from Norway (3), Portugal (6) and the Netherlands (5)
- T2: (directly after last meeting) n =12
- T3: (2.5 - 3 months after last meeting) n=12

- Mean age: 32.5
- 7 male and 7 female
- Concerned about disclosing their psychiatric background
- Diagnosed with a.o. depression, PTSD, ADHD, Addiction, Anorexia Nervosa
Method

- Disclosure-tool
- Group meetings (NO 3; NL 4; PO 8)
- Questionnaires (T1, T2 and T3)

A) Degree of concern (7-point scale)
‘How concerned are you about disclosing your mental health problems to others at school or during your internship?’

B) Decisional conflict scale (O’Connor, 2003)
(16 items; 5 sub-scales; 5-point scale):
- Informed subscale (3): ‘I know which options are available’
- Uncertainty subscale (3): ‘I feel sure about what to choose’
- Values clarity subscale (3): ‘I am clear about which benefits matter most to me’
- Support subscale (3): ‘I have enough support from others to make a choice’
- Effective decision (4): ‘I feel I have made an informed choice’

C) Evaluative questions (T3)
- Strengths and weaknesses
- Recommendations

Results

Does the degree to which the students are concerned about disclosing or not decline after using the disclosure tool? (7-pointscale)
- T1 (n = 14): M = 5.26 (SD=1.08)
- T2 (n = 12): M = 3.83 (SD=1.75)
- T3 (n = 12): M = 3.67 (SD=1.56)

Directly after the last meeting, students are less concerned about disclosing than before the first meeting, t(11) = 2.71, p < 0.03.

Three months after the last meeting, students are still less concerned about disclosing than before the first meeting, t(11) = 4.01, p<0.01.
**Results**

Does the level of experienced Decisional Conflict (uncertainty about a course of action) decline after using the Disclosure-tool?

<table>
<thead>
<tr>
<th></th>
<th>T1 (n = 14)</th>
<th>T2 (n = 12)</th>
<th>T3 (n = 12)</th>
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<tbody>
<tr>
<td>Insecurity</td>
<td>2.98ᵃ (SD=0.91)</td>
<td>2.33ᵇ (SD=0.72)</td>
<td>2.33ᵇ (SD=0.80)</td>
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<tr>
<td>Informed</td>
<td>2.71ᵃ (SD=0.91)</td>
<td>1.89ᵇ (SD=0.81)</td>
<td>2.19ᶜ (SD=1.10)</td>
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<tr>
<td>Values clarity</td>
<td>2.40ᵃ (SD=0.87)</td>
<td>2.22ᵃ (SD=0.67)</td>
<td>1.81ᵇ (SD=0.81)</td>
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<tr>
<td>Support</td>
<td>2.19ᵃ (SD=0.68)</td>
<td>1.83ᵇ (SD=0.64)</td>
<td>1.83ᵇ (SD=0.67)</td>
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<td>Effective</td>
<td>2.00ᵃ (SD=0.61)</td>
<td>2.10ᵃ (SD=0.88)</td>
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<td>Total</td>
<td>2.57ᵃ (SD=0.63)</td>
<td>2.05ᵇ (SD=0.56)</td>
<td>2.05ᵇ (SD=0.65)</td>
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Note. Cell means with different superscripts (per row) differ significantly (p< 0.05)

Students are **less insecure** about their choice; are **more informed** about benefits and risks; **know better** what is more important for them (benefits or risks) feel **more supported** in making a choice; and overall experience **less decisional conflict** after using the Disclosure-tool.

**Current project (april 2016-april 2018)**

- Together with NHL Leeuwarden, University of applied sciences
- Goal: further development, application and evaluation of the Disclosure-instrument
- 14 educational professionals have been trained in applying the disclosure instrument
- Up till now, 34 (out of 50) students with psychiatric disabilities have been supported using the disclosure instrument

**Results**

What are the experiences of the students with the Disclosure-tool?

- Students indicated to experience less anxiety about disclosing, higher level of autonomy
- “I do not feel stressed out anymore; I know that I will not disclose my psychiatric past to my fellow students”
- Tool: Short, clear and concrete. 5 aspects are very useful, especially: whether, what and how.
- Group meeting: + peer support: - more difficult to share everything. Maybe better to have individual meetings.
The overall aim of this project is to develop knowledge regarding the components of Supported Education that are feasible to implement in a Swedish context and to study and describe the relevance of these services for young adults experiencing mental health problems.

### Aim & Method

- The overall aim of this project is to develop knowledge regarding the components of Supported Education that are feasible to implement in a Swedish context and to study and describe the relevance of these services for young adults experiencing mental health problems.

### Background

- A lack of educational opportunities is clearly connected to increased vulnerability, reduced social capital, exclusion from participating fully in the society and worsened mental health (WHO 2012; Olin et al. 2009).
- While young adults with mental health problems are more likely to drop out of school (Harley, 2010) many post-secondary institutions do not offer services readily available to these students (Cross-Matthews et al., 2007).
- Research investigating outcomes related to Supported Employment have begun to suggest the need for more specific, career related, educational supports, as an essential aspect of supporting sustainable employment in a labor market that increasingly demands formal education or training.
- Young adults with mental health problems describe a wish to continue with their education as a first step forward in more natural and age-appropriate roles (Bejerholm & Aresberg 2014; Murphy et al., 2005).

### Results - Study 1 - literature review - preliminary

- **Needs**: Social stressors, accommodations, study environments, lack of readiness & support, navigating the system, stigma
- Great variation in models and even components, outcomes positive, but not sufficiently measurable
- "New" populations – First episode psychosis (Bond et al. 2015), college students, language/culture
- IPS/SED – "hidden", part of IPS/client-centered), belief in integration as viable.
- "Career" – discourse and outcomes (Job/Education fit?); Hegewen et al. (2004).
- Coordination/Needs are determined by local resources
- Coordination impacts choice of, and availability to, various service user groups
Results – Study 2 – Swedish experience – preliminary

- Some IPS services have evolved to include aspects of SEd
- Involvement of guidance counselors, adult education services and municipal vocational svs.
- Flexibility and dynamics between education/employment goals
- The importance of study environments
- New groups – Immigrants with language/migration challenges, Neuropsychiatric (programs in response to Aspergers t.ex.), "non-categorized" potential NEETs
- Funding implications for integrating these services
- Government responsibility variations – Education vs. Employment as societal responsibility?

Discussion/implications

- Explore a variety of adult education possibilities – transitions to adulthood
- Potential for career concept to be developed with these two services integrated
- Balancing “natural” supports and resources and supported environments
- How to describe components and outcomes so that these services become established in Sweden...
- Challenging the welfare system to take a holistic and sustainable, long-term view

Conclusion...

- How can methods such as Supported Employment and Supported Education, which contribute to opportunities for the individual to participate in studies and eventually meaningful and sustainable employment, be most effectively implemented in various welfare systems, include available resources and develop pathways to participation in that context?

- Tack! David.rosenberg@umu.se

Discussion/implications

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- Balancing “natural” supports and resources and supported environments
- How to describe components and outcomes so that these services become established in Sweden...
- Challenging the welfare system to take a holistic and sustainable, long-term view
Thank you for your attention

Lies Korevaar, Jacomijn Hofstra & David Rosenberg

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