### DESCRIPTION OF THE PRACTICE

1. **Title of the practice**
   
   ‘Experiencing citizenship’: developing good practices for inclusive research (Finland)

2. **Organisation responsible for the practice**
   
   Finnish Association on Intellectual and Developmental Disabilities (FAIDD), Finland

3. **Contact person(s)**

<table>
<thead>
<tr>
<th>Name / E-mail</th>
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</thead>
<tbody>
<tr>
<td>Katarina Hakala</td>
</tr>
</tbody>
</table>

4. **Summary of the practice**

   The ‘Experienced citizenship’ research group (hereafter ‘the group’) was set up in the framework of a broader project called ‘Successful Choices’, aiming at ‘Developing the participation of service users in the process of planning their own community-based services’ (2009-2014), especially housing, employment, healthcare and leisure services, as well as schools.

   The group consisted of **four pairs**, each composed of one member of the Finnish Self-advocacy Association of Persons with learning disabilities (ME ITSE) and a partner, friend or carer, chosen by the person.

   The project envisaged to implement a **paradigm shift from dependency**, segregation, passivity and other people knowing ‘what is best for you’, to **participation**, self-determination, control, inclusiveness and ‘expertise by experience’. To do so, each “pair” conducted their own research experiments, in their own communities. A series of 10 workshops was organised in 2013-2014 to study people’s experiences of citizenship, their lives in the community and (obstacles to) participation. The workshops involved people with disabilities as research partners, through discussions and using cartoons as a method for analysing research data.

   The objective was to find a successful, collective and properly inclusive research methodology.

5. **National/regional/local context of the practice**

   The methodology for “inclusive research” (e.g. Walmsley & Johnson 2003) has been developed to provide guidance on how to do research together with people with learning disabilities, and better include their perspectives in the research, planning and implementation of disability services. This also follows a **human rights based approach**, in line with international frameworks such as the UN Convention on the Rights of Persons with Disabilities.

   It is based on the **social model of disability**, where disability is viewed as caused by the way society is organised, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for disabled people.

   The 2010-2015 Finnish programme for disability policy, based on the UN CRPD, was the starting point of the initiative.

6. **Staff involved**

   Besides the four pairs, the project involved:
   
   - one cartoon teacher,
   - one social work student, and
   - one researcher,
FAIDD is a member of the Nordic Centre of Excellence’s JUSTED network (Justice through education in the Nordic Countries), a multidisciplinary, cross-national research network of 14 partners, coordinated by the Institute of Behavioural Sciences of the University of Helsinki.

The "Experienced citizenship" research was conducted within the FAIDD’s project, but the results have been presented and shared within the whole JUSTED network. The “Inclusive research as doing justice through education” symposium was organised around the project, which was presented at the JUSTED conference in March 2016. The symposium featured eight presentations introducing different perspectives and researchers doing inclusive research from Iceland, Great Britain and Finland.

7. Target group

All those involved in the disability service system at all levels: people with learning disabilities, their support persons and families, service planners, policy makers, etc. in Finland.

8. Aims of the practice

Developing a successful, collective and properly inclusive research methodology to involve people with learning disabilities.

9. Issues for social services

<table>
<thead>
<tr>
<th>Service Integration/ Cooperation across services</th>
<th>Service Planning</th>
<th>Contracting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Technology</td>
<td>Skills development (of the workforce)</td>
<td>Quality of services</td>
</tr>
<tr>
<td>Others: service user involvement</td>
<td>x</td>
<td></td>
</tr>
</tbody>
</table>

10. Status

<table>
<thead>
<tr>
<th>Pilot project (ongoing)</th>
<th>Project (ongoing)</th>
<th>Implemented practice (restricted areas)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilot project (terminated )</td>
<td>Project (terminated)</td>
<td>Widely spread practice/rolled out</td>
</tr>
</tbody>
</table>

11. Scope of the practice

Describe the setting of the practice, considering the following criteria:

- **Micro level practice**: practice that involves individuals at local level
- **Meso level practice**: practice that involves organisations or communities
- **Macro level practice**: practice that involves large population groups

The project started at meso level, working in two Finnish municipalities. It was then presented and discussed at several seminars and conferences both nationally and internationally. The final report is available online, in Finnish, to all authorities and professionals.

12. Leadership and management of the practice

Description of the leadership of the practice, considering the following criteria:

- **Collaborative management**: shared between large partnerships, often of central, regional and local representation
- Organisational management: by one organisation
- Professional management: managed by a single person
- Shared management: shared with no defined leadership

The group leader paid specific attention to truly empower group members in taking part in the formulation of research questions. They started by studying and discussing, together, the easy-to-read version of the UN Convention on the Rights of Persons with Disabilities (UN CRPD), and what each of the articles meant for group members.

The whole project was managed by FAIDD education and development unit. The research group was led by FAIDD’s senior researcher. The four research experiments were planned and conducted together, leaving as much leadership as possible to group members themselves.

### 13. Engaging stakeholders in the practice

**Description of the engagement of stakeholders, considering the following criteria:**

- **Individual practice**: individuals have sought practice change
- **Network approach**: one or more organisations develop a network
- **Collaborative approach**: large collaboration with relevant stakeholders

Each of the 4 pairs involved in the project consisted of one person with learning disabilities and a person they chose to work with: a partner, a special teacher, a holiday care home hostess, a personal assistant, a friend and a member of an association of parents of people with learning disabilities.

The four research exercises engaged several stakeholders in group members’ home communities. They were reported as stories of the process when studying:

- Personal experiences of one group member when moving from an institutionalised, segregated life setting to a community-based, new group home. The exercise involved visits in the institution and the group home, meeting and discussing with the workers and other service users there.
- Another group member wrote stories about being raised in an orphanage and becoming an active member of a self-advocate association. The “Song of Stories” was edited and the manuscript was printed for the author.
- Experiences of independent living of four young women living in supported housing/group home for young people leaving their family home and learning independence.
- A couple, living together independently and using disability services, studied the process of service planning, and the needs’ assessment and care plan process, together with a support worker.

### 14. Involvement of service users and their families

**Description of the involvement of service users, considering the following criteria:**

- **Team involvement**: service users and carers were part of the practice team
- **Consultative**: a consultative body of users was set up for an on-going dialogue and feedback
- **Involvement in care**: person-centred approaches to care/support

Collaboration of service users and their communities was the very starting point of the project.

### 15. Costs and resources needed for implementation

**Description of how the practice is financed, considering the following criteria:**

- **Within existing resources**: staff time and other resources are provided ‘in-house’
- **Staffing costs**: costs for staff investment
- **Joint/Pooled budgets**: two or more agencies pool budgets to fund services
The project was funded by the Finnish Slot Machine Association (RAY 2011-2014).

### 16. Evaluation approaches

Description of the evaluation method of the practice, considering the following criteria:

- **Multi-method**: use of both a qualitative and a quantitative approach
- **Single method**: qualitative or quantitative approach
- **Audit**: looks at data sources such as existing medical records, and/or other routinely collected service data.
- **Informal**: refers to in-house service evaluation using locally designed tools and/or collecting opportunistic feedback
- **No evaluation**
- **An evaluation is planned**

### 17. Measurable effects of the practice and what it has achieved for...

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service users</td>
<td>n. a.</td>
</tr>
<tr>
<td>Formal care givers</td>
<td>n. a.</td>
</tr>
<tr>
<td>Informal carers</td>
<td>n. a.</td>
</tr>
<tr>
<td>Organisations</td>
<td>n. a.</td>
</tr>
<tr>
<td>Other</td>
<td>n. a.</td>
</tr>
</tbody>
</table>

### 18. Anticipated or 'aspirational' effects of the practice and what it has achieved for...

This category can include outcomes which are not documented, quantified or properly evaluated. They can include such elements as improved knowledge, quality, workforce, etc.

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service users</td>
<td>Empowerment, feeling of self-confidence and expertise.</td>
</tr>
<tr>
<td>Formal care givers</td>
<td>n. a.</td>
</tr>
<tr>
<td>Informal carers</td>
<td>n. a.</td>
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<tr>
<td>Organisations</td>
<td>n. a.</td>
</tr>
<tr>
<td>Other</td>
<td>n. a.</td>
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</table>

### 19. How the practice has changed the way the service is provided (lessons learned)

n.a.

### 20. Sustainability of the practice

Description of whether the practice is sustainable, considering the following criteria:

- **Potential for sustainability**: practice was newly started or is on-going/not yet mainstreamed. How could the practice be sustained (in terms of resources)?
- **Organic sustainability**: service users have been empowered to take the practice forward
- **Established**: the project has been operational for several years

FAIDD is working on a ‘multimedia’-reporting of the research group and the research experiments conducted in it. This needs extra funding and they are currently applying for renewed funding.
This multimedia, or parts of it, could easily be translated to or subtitled in English.

### 21. Transferability of the practice

*Description of whether the practice has been transferred, considering the following criteria:*

- **Transferred:** transfer to other regions, countries, service user groups, etc.
- **Potential for transferability:** there is interest from the outside; elements of the practice have been taken up and used elsewhere; material for transferability (for ex. training material) has been developed