

# WellSEQ

A self report tool to measure the well-being of adolescents with intellectual or developmental disability

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# Contents

- Psychological Well-being in IDD
- Well-being Measures
- Our research



## Developmental Disabilities

- Intellectual Disability
- Autism Spectrum Disorder
- Cerebral Palsy
- Down Syndrome
- Fragile X



# WELL-BEING IN IDD

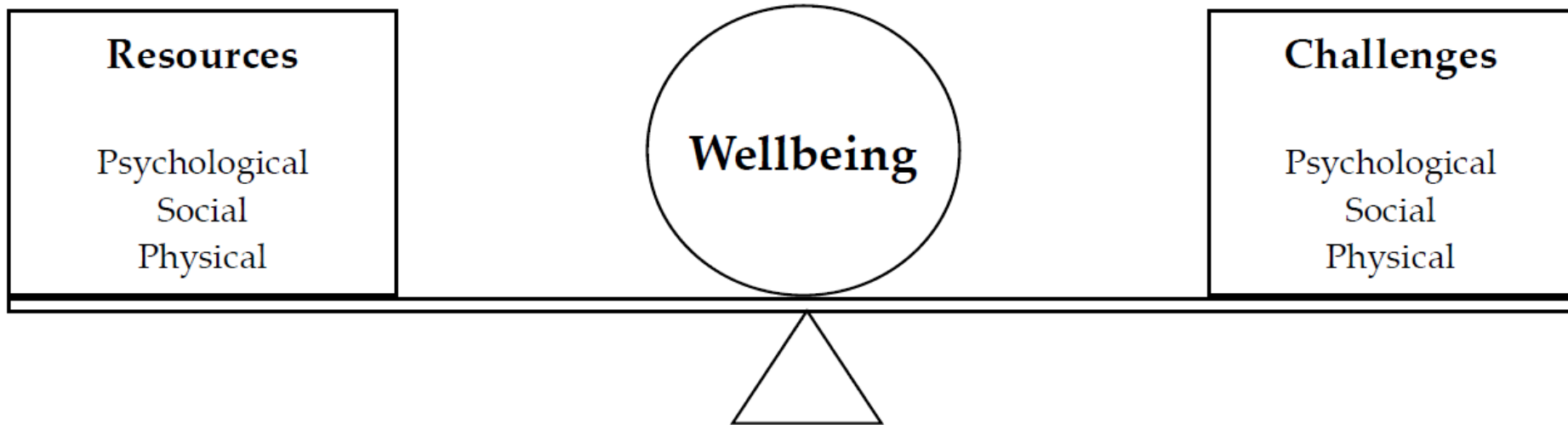


# What is Wellbeing?

- How people feel, how they function (connectedness), and how they evaluate their lives as a whole (satisfaction) (NEF)
- Well-being as an overall experience of life, including but not solely defined by health or income status, and able to be understood by the level of experience of a range of human rights and opportunities (ARACY).



# Well-being

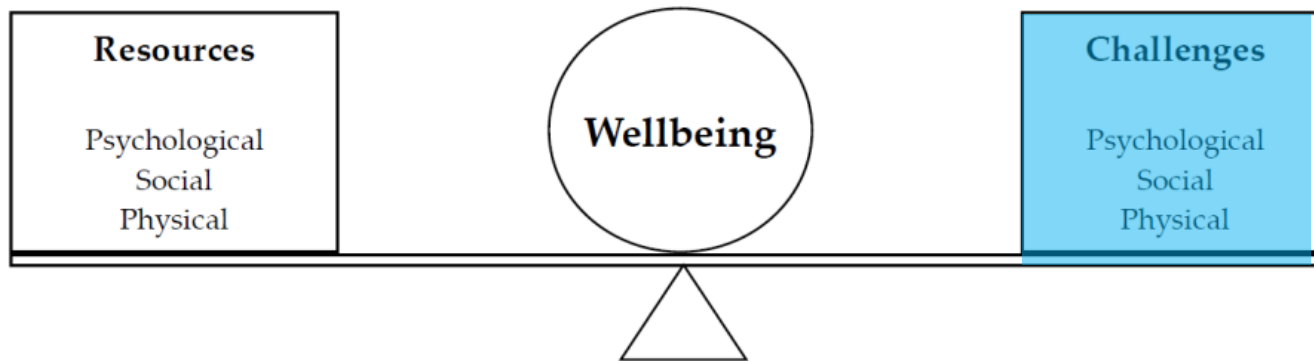


The balance point between an individual's resource pool and the challenges faced.

(Dodge, Daly, Huyton & Sanders 2012)



# The challenges



# Individual Challenges

## RISK FACTORS

- prenatal brain damage
- prematurity
- birth injury/ complications / low weight
- physical/ intellectual disability
- poor health in infancy
- insecure attachment in infant/child
- low intelligence
- difficult temperament
- chronic illness
- poor social skills
- low self –esteem
- alienation
- impulsivity





# Family/ Social Factors

## RISK FACTORS

- having a teenage mother or single parent
- absence of father in childhood
- large family size
- antisocial role models
- family violence/disharmony, marital discord
- poor supervision & monitoring of child
- low parental involvement
- neglect in childhood
- long term parental unemployment
- criminality in parent
- parental substance misuse and/or mental disorder
- harsh or inconsistent discipline style
- social isolation
- experiencing rejection
- lack of warmth and affection



# School Context



## RISK FACTORS

- bullying
- peer rejection
- poor attachment to school
- inadequate behaviour management
- deviant peer group
- school failure

(Commonwealth Department of Health and Aged Care 2000)



# Life Events & Situations



## RISK FACTORS

- abuse
- school transitions
- divorce/family breakup
- death of family member
- physical illness/ impairment
- unemployment/ homelessness
- incarceration
- poverty / economic insecurity
- job insecurity
- unsatisfactory work relationships
- caring for someone with a disability
- war or natural disasters



# Community & Cultural Factors



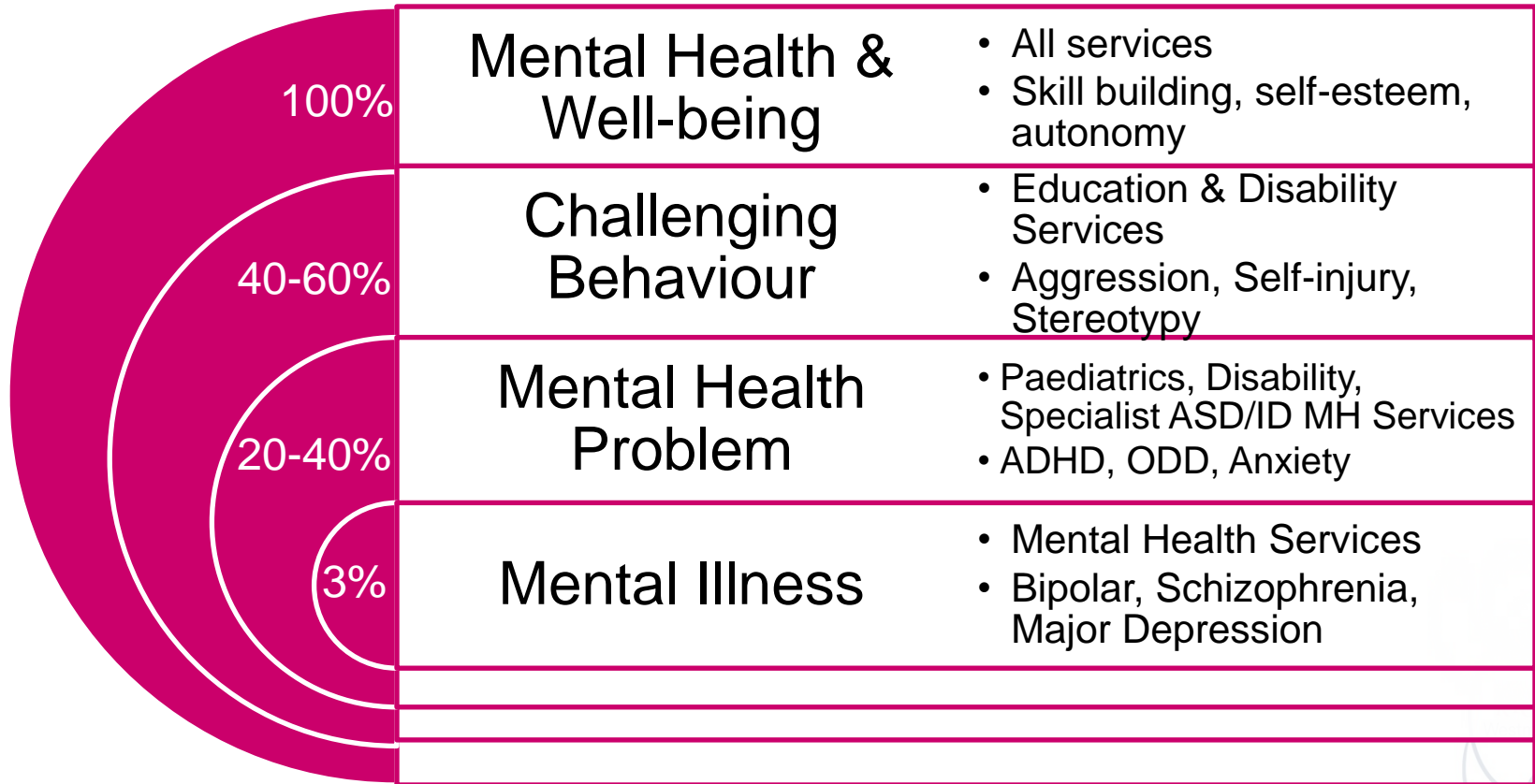
## RISK FACTORS

- socioeconomic disadvantage
- social or cultural discrimination
- isolation
- neighbourhood violence and crime
- population density and housing conditions
- lack of support services including-  
transportation, shopping, recreational  
facilities

(Commonwealth Department of Health and Aged Care 2000)



## Mental Health Severity and Students with Autism/Intellectual Disability Dossetor (2016)



# The resources



# Individual Resources

## PROTECTIVE FACTORS

- **adequate nutrition**
- **attachment to family**
- **problem-solving skills**
- **social competence/ skills**
- easy temperament
- good coping style
- optimism
- moral beliefs
- values
- above average intelligence





# Family/ Social Factors



## PROTECTIVE FACTORS

- **supportive caring parents**
- **responsibility within the family**
- **supportive relationship with other adult**
- **strong family norms and morality**
- **family harmony**
- **secure and stable family**
- **small family size**
- **more than two years between siblings**





# School Context



## PROTECTIVE FACTORS

- **sense of belonging**
- **positive school climate**
- **pro social peer group**
- **required responsibility and helpfulness**
- **opportunities for some success and recognition of achievement**
- **school norms against violence**

(Commonwealth Department of Health and Aged Care 2000)



# Life Events & Situations



## PROTECTIVE FACTORS

- involvement with significant other person (partner/mentor)
- availability of opportunities at critical turning points or major life transitions
- economic security
- good physical health

(Commonwealth Department of Health and Aged Care 2000)



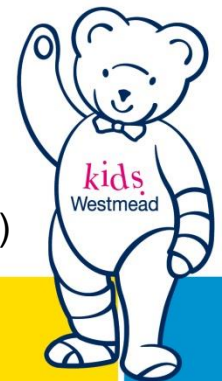
# Community & Cultural Factors



## PROTECTIVE FACTORS

- sense of connectedness
- **attachment to and networks within the community**
- participation in community group
- strong cultural identity and ethnic pride
- **access to support services**
- community/ cultural norms against violence

(Commonwealth Department of Health and Aged Care 2000)



# WELLBEING MEASURES



# Types of assessment

- Parent report
- Teacher report
- Self-report



# Existing Proxy Measures

*Proxy: teacher and parent*

- The Developmental Behaviour Checklist (Einfeld & Tonge)
- Strengths and Difficulties Questionnaire (SDQ)



# Existing Self Report Measures

- Strengths and Difficulties Questionnaire  
Adolescents aged 11-17
  - Tested on 11-15 yr olds with ID by interview  
(Emerson 2005) privacy + labour
- Glasgow anxiety and depression scales (adult)
- How am I feeling? (anxiety and depression)



# Problems with existing questionnaires

- Linguistic complex questions
- No visual supports
- Response scales based on abstract reasoning
- Limited attention span
- Privacy





# Well-being in Special Education Questionnaire

- The WellSEQ is a 42-item questionnaire on tablet
- Measures self-rated mental health and ill-health, peer relations/conflict, school and family environment
- Adolescents with mild or moderate IDD aged 12-16 years
- Developed by University of Gothenburg (Bostrom and Eriksson 2015) and is currently available in Swedish only!









Känner du dig ensam?

Nej

Ibland

Ja

## Friend relations and conflicts

<p>Do you have a really good friend?</p>	
<p>Do you have difficulty making friends?</p>	
<p>Do others seem to like you?</p>	
<p>Do you feel lonely?</p>	
<p>Do you get support from your friends when you need it?</p>	

<b>Problem</b>	<b>WellSEQ solution</b>
Linguistic complex questions	✓ Easy read
No visual supports	✓ Photographs
Reading ability	✓ Voice option to read questions to student
Limited attention span	✓ Fewer questions presented one at a time
Response scales based on abstract reasoning	✓ 3 likert scales “yes, no, sometimes”
Lack of privacy	✓ Can be completed independently from start to finish

## Swedish Research

- 18 schools, 113 students 12-16 years in special education classes.
- 71% male
- Additional diagnosis
  - Only IDD 13.3%
  - ASD 27.4%
  - Down Syndrome 24.8%



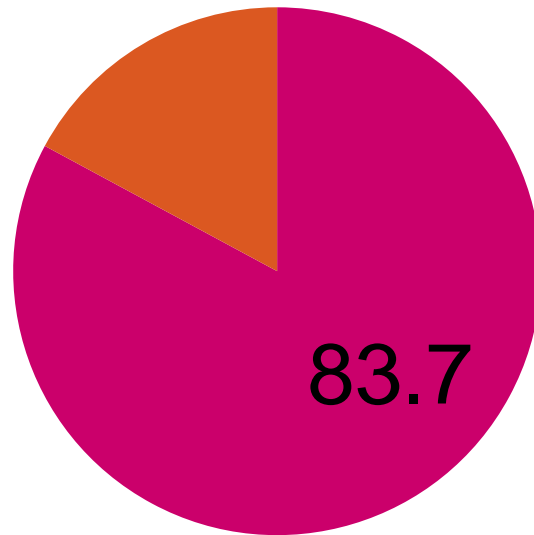
## Results

- 96.5% 109 students completed all of questionnaire (4 missing data)
- 2 children needed assistance
- Time taken was 4 to 18 minutes (mean 7.6)
- Positive correlations between parent/teacher WellSEQ and SDQ



# Positive Response Bias

**Response to reverse worded question:** *Is it hard for you to make friends? Vs Is it easy for you to make friends?*



- consistent
- inconsistent



# Adolescent proxy agreement

Scale	Adolescent-parent	Adolescent-teacher
Mental Health	x	✓
Mental ill health	x	x
Peer relations	x	x
Family Environment	x	-
School Environment	✓	✓





# OUR RESEARCH



## Our research

- Is the English version of the WellSEQ an acceptable translation from Swedish to English for adolescents aged 12-16 with IDD?
  - Part A
  - Part B
  - Part C



# The Research

PART A: Official translation and comparisons



PART B: Workshops with students  
with IQ (40-55 and 55-70)



PART C: Pilot testing of questionnaire with students  
with IQ (40-55 and 55-70)



Production of WellSEQ - ENG with Sweden



## Benefits of research

- Once complete identify/screen mental health
- Potential to monitor school population over time
- Children with IDD can participate in population surveys
- Add to Swedish/international data pool



## Conclusions

- Early identification and treatment of mental health is important for well-being
- WellSEQ, a reliable self report measure where none exist
- Further research needed to explore construct validity
- Bring on the English translation research
- Possibilities for other groups?



## For more information

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