

Bullying Experiences of Youth with Neuromuscular Conditions: Youth and Parent Perspectives

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Background

Bullying is a pervasive and harmful experience for youth with neuromuscular conditions (NMC).¹

Current Understanding & Gaps in Knowledge

- Effects of bullying include: ↓ physical and mental wellbeing, strained social relationships, ↓ academic performance, ↓ adult health outcomes.²
- Parental intervention is protective against bullying.³
- However, the **impact of bullying** on the social lives of youth with NMC **may not be fully captured by caregivers**.

Research Question

Does **perception of bullying** and **quality of life** between **youth** with NMC and their **parents** differ?

Methods

Study Population

22 youth + parent dyads
44 total responses

Youth Demographics

81.8% male respondents

10-18 years old
Mean_{age} = 14.1 years

45.5% use a mobility device
e.g., wheelchair, walker

Inclusion Criteria

Diagnosed NMC
e.g., Duchenne muscular dystrophy, Myotonic dystrophy

Parent Demographics

77.2% parental responses were from mothers

Survey Items

Youth and parents responded to a survey addressing youth’s bullying experiences (type, frequency, motive) and QoL.

- Youth and parent demographics
- Bullying prevalence and experiences ***
- Number of friends
- Perceived bullying motives ***
- KIDSCREEN-10 Questionnaire ***
 - Perceived loneliness *

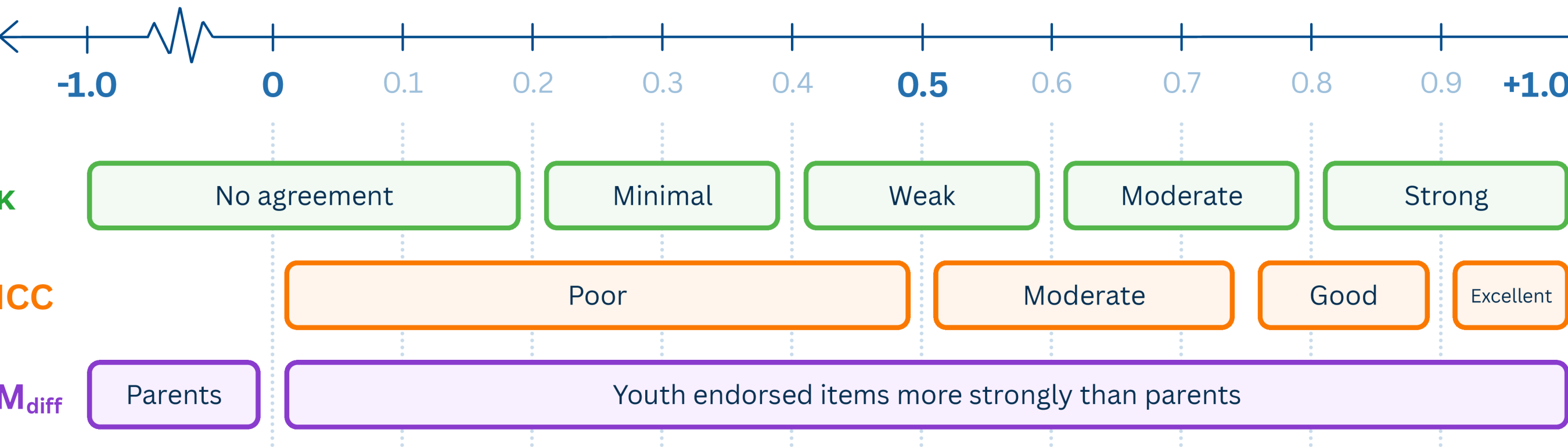
About the KIDSCREEN-10 Questionnaire

- Measures QoL:
 - Psychological Well-being
 - Parent Relations & Home Life
 - School Environment
 - Physical Well-being
 - Social Support & Peers
- Rasch model analysis allows score comparison against international reference populations.

* Responses scored on a 5-point Likert scale, where 1 represents lowest endorsement of item.

Statistical Analysis and Interpretation

Measure	Insight
Percent Agreement (PA)	Total raw agreement across dyads
Weighted Quadratic Cohen's Kappa (κ)	Gold standard dyad agreement; accounts for chance agreement
Intraclass Correlation Coefficient (ICC)	Dyad agreement for scale data; accounts for chance agreement
Mean Response Difference (M _{diff})	Directionality; which group endorsed items more strongly



We learned:
Youth with neuromuscular conditions view bullying experiences and quality of life differently than their parents.



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- Abstract
- References
- Acknowledgements
- Ward Program Information and Biographies

...and more!

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Results

Trends in Dyad Agreement

- 77%** of youth and **86%** of parents reported youth were **bullied at some point** in their life.
- Shared experiences** (e.g., race, religion) yielded **strongest dyad agreement** on bullying motives.
 - Discrepancies exist across youth-specific experiences (e.g., disability, appearance).
- Zero dyads agreed on loneliness** (PA=0.0%; κ=-0.262 [p<0.001]; M_{diff}=1.86).
- Every parent underestimated QoL** (PA=0.0%; ICC=0.475 [p<0.001]; M_{diff}=7.15).

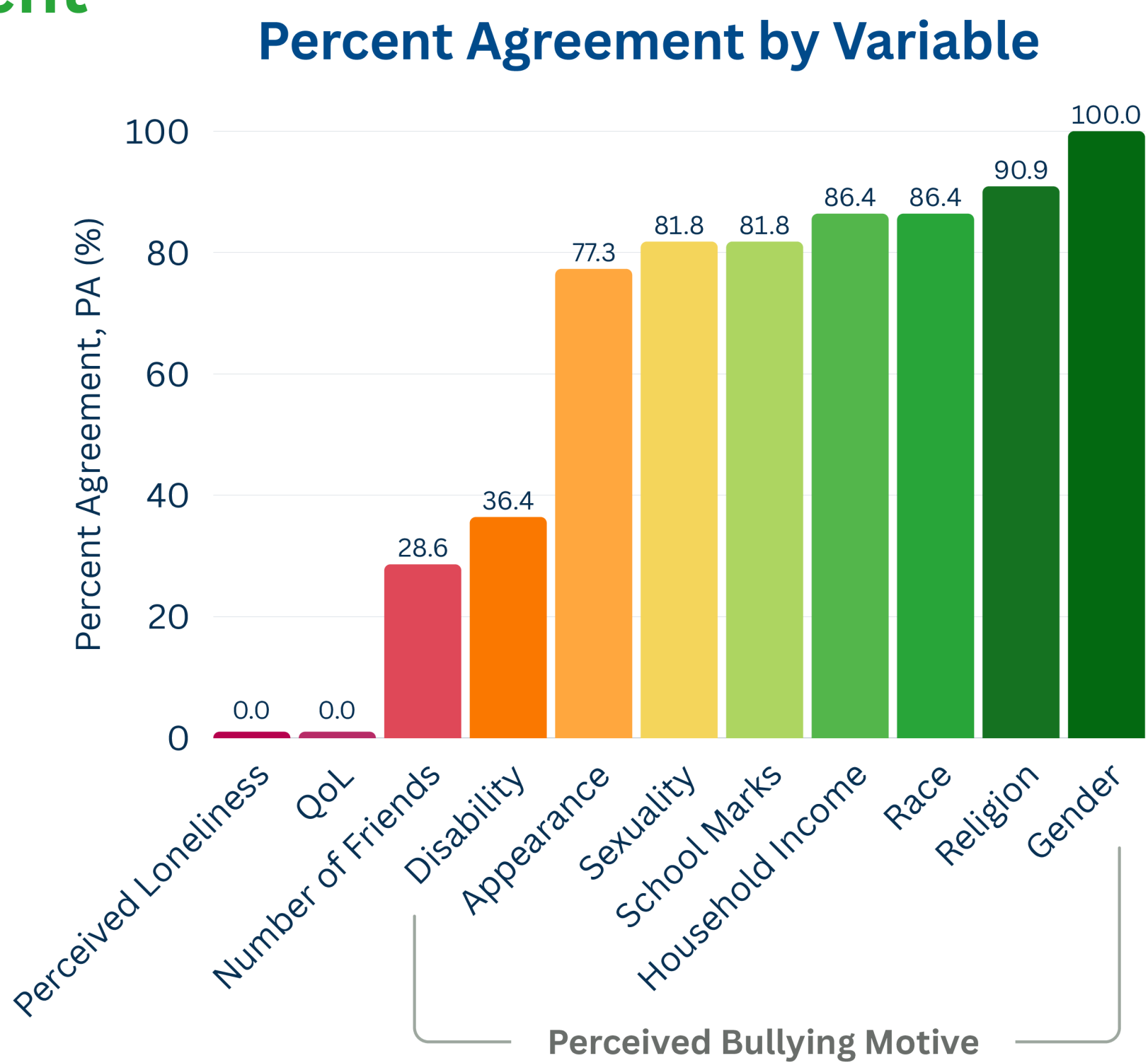


Figure 1. Percent agreement across parent-youth dyad responses, ordered from least to greatest agreement.

Dyad Agreement by Cohen’s Kappa, Intraclass Correlation Coefficient, and Mean Response Difference

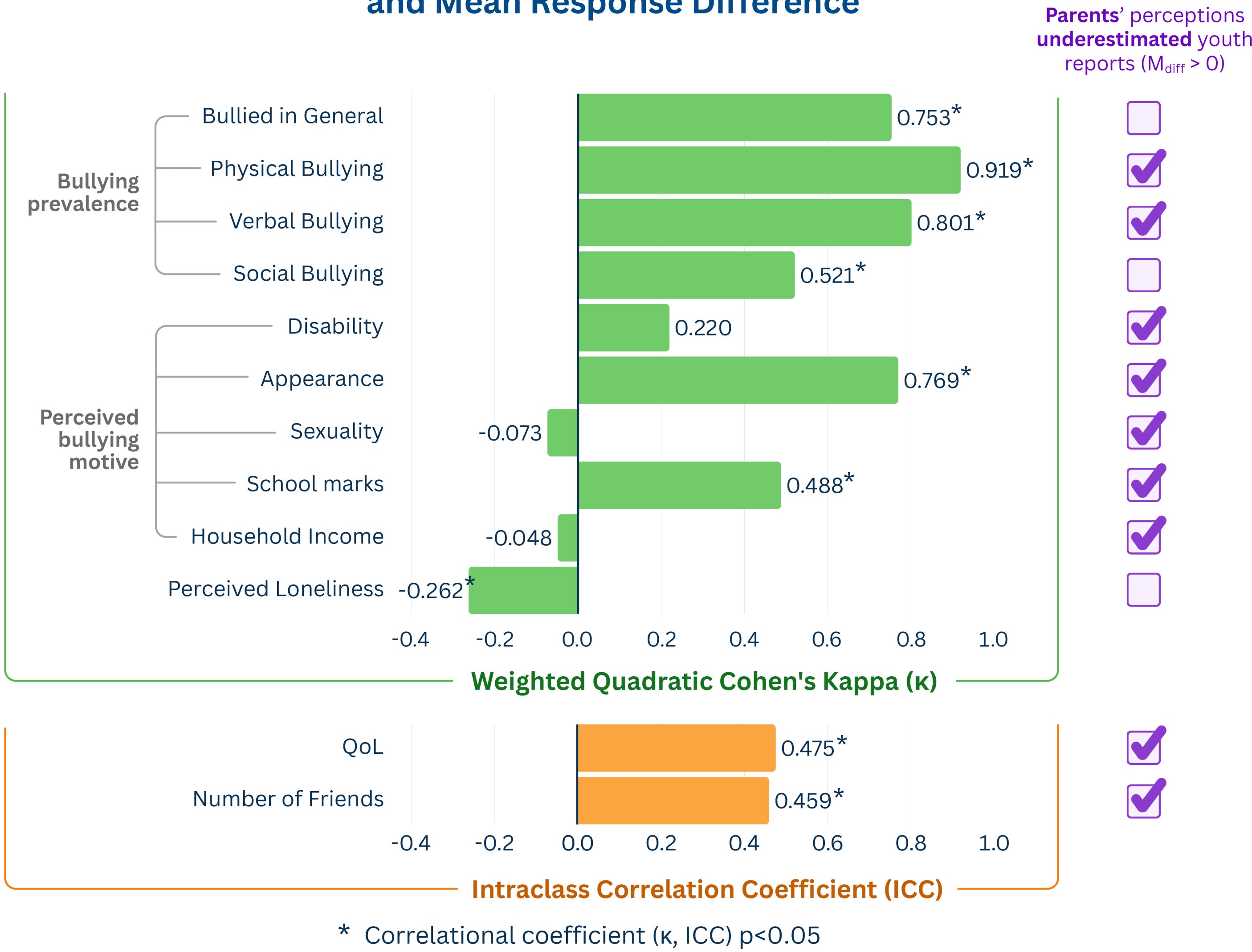


Figure 2. Agreement between youth and parent dyad responses measured using Weighted Quadratic Cohen’s Kappa (κ) and Intraclass Correlation Coefficient (ICC). Ticked boxes report positive Mean Response Differences (M_{diff}), highlighting items affirmed more by youth than by parents. Asterisks (*) denote significance representing dyad agreement beyond chance (p<0.05).

Conclusions

Strong Agreement

- Bullying due to experiences shared by youth and parents (e.g., race, religion)
- Bullying prevalence

Weak Agreement

- Bullying due to experiences unique to youth (e.g., disability, appearance)
- Loneliness and friendship
- QoL

Future Directions: Explore if dyad agreement may be associated with youths’ bullying experiences and victimization disclosure.

Relevance

For Clients and Families

Strengthen shared understanding

- Youth**
 - Affirms the **importance of youth voice** to shape meaningful support.
- Parents**
 - Encourage open conversations** about psychosocial experiences, particularly when parents are proxy advocates for youth.
 - Reflect on how youth define quality and depth of social interactions.

For Clinicians

Promote family-centred care

- Appreciate the value of **integrating youth self-reports and parent observations** to inform assessment and care.
- Support families in **creating space for youth to express** their views and experiences.

For Researchers

Inform design and interpretation of QoL measures

- Inform **development and utilization of psychosocial assessments** used in pharmaceutical and clinical research to reflect lived realities of youth with NMC.
- Avoid **over-reliance on proxy reporting alone** for outcomes with low agreement.