

The Need for Norming Instruments That Measure Inclusion Activities Among People Who Have Intellectual Disability

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Abstract

More attention has been brought towards efforts to better integrate people with Intellectual Disability (ID) with the rest of society. Part of this integration is understanding the similarities and differences in the number of interactions that people with Intellectual Disability and the normative population have in various scenarios. In the absence of normed scales measuring inclusion, community participation data collected from 2005 people with Intellectual Disability were compared with data from a variety of samples of members of the general public. Studies suggest a means by which inclusion data might be interpreted. Preliminary results suggested that people with Intellectual Disability participated in social community events slightly more than the general public but slightly less in life support events such as grocery shopping. This study provides insight into how people with Intellectual Disability interact in different community settings, but also a greater need for more public data on average interaction data from the general population as a whole.

Introduction

Inclusion and equitable community participation have been cornerstones of the deinstitutionalization movement in the Intellectual Disability field. The deinstitutionalization movement of the 1960s and 1970s was driven by concerns regarding quality of care, unnecessary segregation, and the belief that better alternatives existed. Thaler (1991) summarized the new mission of Intellectual Disability services in the document “Everyday Lives.”

Conroy and Bradley conducted one of the early large-scale evaluations of the deinstitutionalization movement, focusing on the life outcomes for persons discharged from the Pennhurst Center in Spring City, PA (Conroy and Bradley, 1985). They employed a multitude of outcome indicators in their study, including a series of questions that specifically addressed community involvement. Specific items included:

- Inclusion in community activities
- Changes in adaptive behavior
- Type of Day Activity
- Satisfaction with Life Quality
- Ability to make and implement decisions

Other researchers have followed in this tradition of attempting to monitor the extent to which these formerly segregated individuals were able to participate in the general community. Most notably, the National Core Indicators project (National Core Indicators-Aging and Disabilities, 2023) regularly addresses a sample of inclusion questions in their annual surveys. Given the size of their sample and the fact that it approximates a national sample, it is reasonable to suggest that the National Core Indicator data are perhaps the most reliable and valid estimates of inclusion that are currently available.

Returning to the Conroy and Bradley Pennhurst study (1985), note that the researchers also studied changes in adaptive behavior over time. As a measure of personal competence, a desired outcome in adaptive behavior would be a documentable increase in personal skills, with adult Americans typically earning a perfect (or near-perfect) score on most measures of adaptive behavior (Spreat, 2017). Norming is not a particularly relevant construct with reference to adaptive behavior because the real norm approaches absolute performance. Adaptive behavior is not normally distributed. Simply put, the higher the adaptive behavior score, the better the welfare and independence of the individual.

Inclusion metrics, however, do not approach maximal outcomes for any population. Norming among the general population is really needed in order to interpret scores obtained in studies such as those conducted by NCI and Conroy & Bradley (1985). The goal of inclusion is not so much to maximize inclusion but rather to attempt to match the extent of the community participation rate achieved by members of the general public who do not experience disabilities. Ultimately, the goal of the inclusion movement is to promote an everyday sort of life (Thaler, 1991).

Norming of inclusion expectations is absolutely necessary in order to interpret the findings of inclusionary studies in the Intellectual Disability field. Going to the movies 50 times per month is not so much the goal as going to the movies about as often as everyone else does. Unfortunately, none of the more typically used inclusion scales are normed with a general public population. Without data that address normative expectations for inclusion, it is not really possible to interpret findings for inclusion studies involving people with Intellectual Disability.

To date, no one has established normative expectations for inclusionary community-based activities. The purpose of this study was to attempt to locate publicly available data that offer insight into the extent to which members of the general public actively participate in community events that are typically listed in measures used to quantify inclusion in the Intellectual Disability field. Conroy's (1997) scale on integration activities served as the starting point for the investigation. This scale has been used in many large-scale studies in the United States, and its content is typical of other measures of social inclusion. Conroy's scale contains 15 discrete questions on the frequency of inclusion. A general description of each item appears in the table below. The task at hand was to attempt to locate empirical data that might yield some suggestion of the extent to which members of the general public participate in the activities listed in the Conroy (1997) scale.

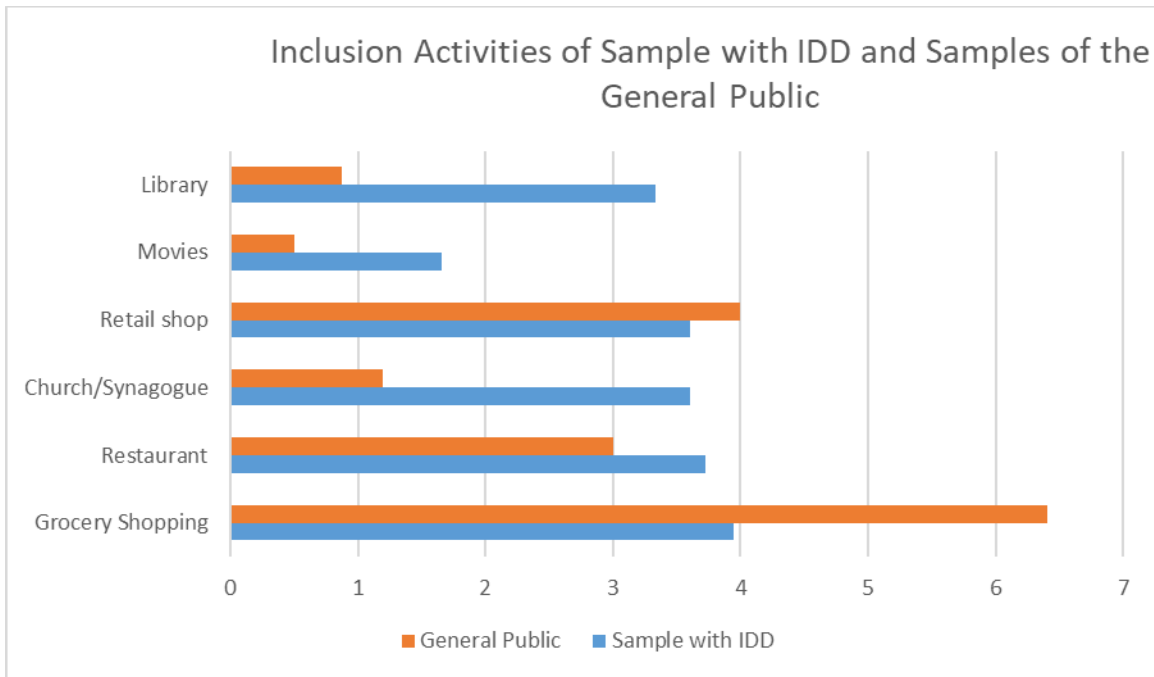
Conroy’s scale on integrative activities included 15 discrete questions. Responses to each item were framed in terms of the monthly frequency with which a given individual participated in that activity. The questions are listed in the table below.

Items included in Conroy’s 1997 Integrated Activities Scale
1. Visit with close friends, relatives, or neighbors
2. Visit a grocery store
3. Go to a restaurant
4. Go to church or synagogue
5. Go to shopping center, mall, or other retail store to shop
6. Go to bar or tavern
7. Go to a bank
8. Go to a movie
9. Go to a park or playground
10. Go to a theater or cultural event (includes local)
11. Go to a post office
12. Go to the Library
13. Go to a sporting event
14. Go to a health or exercise club, spa, or center
15. Use public transportation

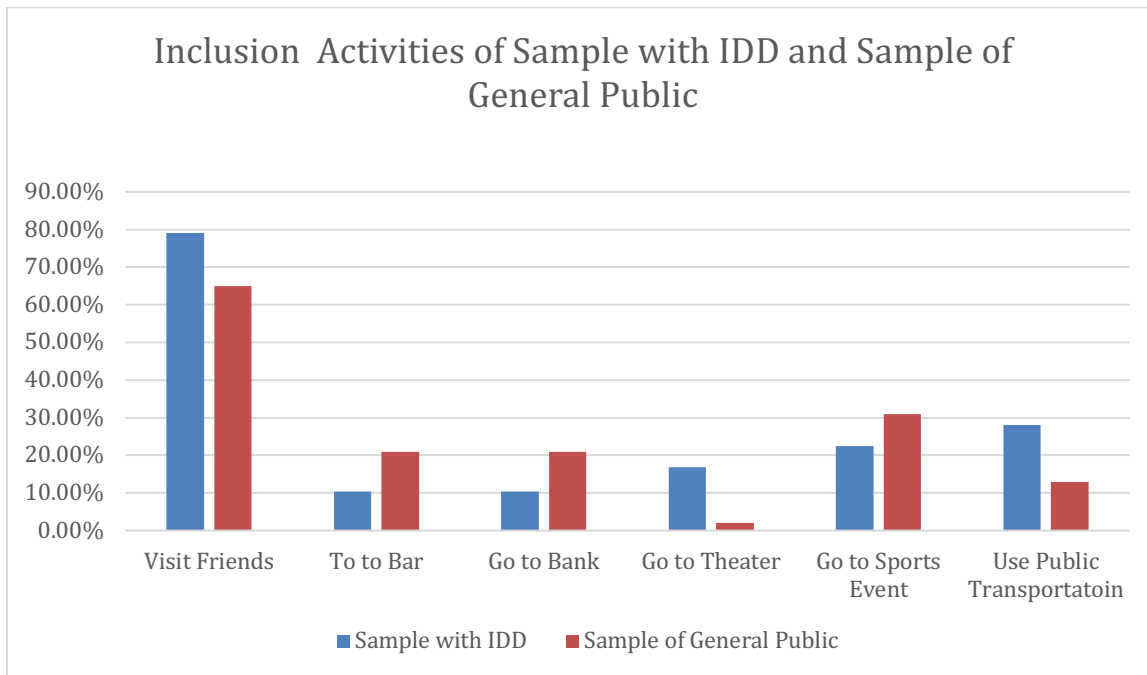
In an effort to establish rudimentary normative expectations for community inclusion and integration efforts, a search was conducted to locate surveys of the general public that addressed items similar to those in Conroy’s (1997) scale. Sources varied widely, often coming from industry surveys. The following surveys contributed to the estimation of everyday life inclusion/integration activities:

- Civic Science (2023) survey on socialization
- NASDAQ (2023) survey on grocery store use
- USFoods (2023) survey on restaurants
- Gallup poll (2010) survey on church attendance
- ICSC survey (2015) of shopping frequency
- World Metrics (2024) survey on bars and taverns
- Forbes (2023) survey on bank use
- Popflick survey (2022) on movie attendance
- National Recreation and Parks Association survey (2019) on park use
- Statistica (2013) survey on theater/cultural event attendance
- USPS (2023) survey on the use of post office
- Gallup Poll (2019) survey on library use
- Sports Business Journal (2023) report on attendance at professional sporting events
- Media Market (2021) report of gym and spa attendance
- APTA (2024) report on the use of public transportation

The findings of the review of surveys done with the general public were compared with findings reported in a statewide survey of the Intellectual Disability system in mid-western states. The table immediately below depicts those Conroy items for which estimates of monthly participation frequency were available for both the sample with Intellectual Disability and a sample of the general public. Note that each question relied on a different sample for the general public.



There were several items for which the responses of the general public were quantified in terms of the percentage of individuals who did attend the events. They were not reported as monthly counts. Where necessary, the data were converted to the percentage of people who attended in any given month. Similar adjustments were made for the data from the Intellectual Disability sample. This information is presented below:



Utility of these data

This is admittedly a rudimentary effort to attempt to impose some limited degree of interpretability on Intellectual Disability inclusion and integration data. The limitations of these data must be recognized, and it must be understood that their value derives solely from the complete absence of normative data on scales typically used in the Intellectual Disability field. Certainly, they do not constitute a satisfactory norm group, but they do offer some preliminary suggestions for the interpretation of data collected from people who have Intellectual Disabilities. Ideally, the better solution would be to collect normative data from a large sample using Conroy’s scale. In this manner, evaluators might be better able to assess the outcomes associated with efforts to include people with Intellectual Disability in community activities.

Subjectively examining the discrepancies between the sample with Intellectual Disability and the samples from the general public, there is the modest suggestion that people with Intellectual Disability have the opportunity to participate in increased levels of socialization activities such as going to the Library, Movies, or Church. Members of the general public appear to devote greater effort to maintenance activities, such as grocery shopping.

Considerable caution needs to be exercised with regard to these data. The intent is not so much to establish an alternative approach for establishing socialization norms but rather to call for the norming of scales that attempt to quantify the extent to which individuals with Intellectual Disability participate in community integration activities. Ultimately, the goal is to promote socialization/integration activities that essentially match the participation level of members of the general public. To do this, it is essential to establish norms for scales that measure inclusion/integration activities.

Overall, this analysis has some limitations. First, without having a true norm group, percentile rankings cannot be acquired. Because of this, analysis was limited to subjective ratings of above, at, or below average when comparing norm data to survey data. Also, the samples are not truly from the norm group but rather from those who responded to the survey. There is bias based on the people who respond to surveys versus those who don't, so there is potential for different perspectives to be missed out on because of those who did not respond to the survey. To help mitigate this, a true norm group needs to be established, but the difficulty of that ties into the difficulty of survey responder bias.

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