

Presuming Competence in Clinical and Educational Evidence

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Abstract

People with significant communication differences and impaired or emerging decisional capacity are systematically underrepresented in the evidence that governs their lives. A child with autism who does not speak, an adult with moderate dementia, a person with intellectual disability: each is routinely excluded from clinical trials on capacity grounds and routinely represented in educational research through adult proxies rather than through their own account. The exclusion is usually framed as protective. This conceptual paper argues that it is better understood as a methodological failure with ethical consequences, and that the two fields most responsible for it, clinical research and special education, have each developed partial remedy that the other has never adopted. The paper proposes presumed competence as a methodological commitment rather than only a moral posture, meaning a default assumption that the person has a perspective worth eliciting, combined with an obligation to adapt method until elicitation succeeds or is demonstrably impossible. Six domains are developed: the structure of the shared exclusion problem, presumed competence as method, consent and assent as continuous processes, partner-dependent expression and the validity of the record, proxy report and the measurement of outcomes that matter, and participatory design as a redistribution of research authority. Each domain identifies what clinical research has built that special education lacks, and what special education has built that clinical research lacks. The paper concludes with implications for protocol design, ethical review, measurement selection, and workforce preparation, and specifies testable propositions.

Keywords: *competence, consent, assent, augmentative, alternative communication, proxy, participatory, intellectual, disability, dementia*

1. Introduction

Evidence is supposed to represent the people it governs. In two fields concerned with some of the most vulnerable populations in health and education, it frequently does not. An adult with

moderate dementia is screened for a study of symptom management in advanced illness. She is excluded because she cannot complete the capacity assessment the protocol requires. The trial proceeds, produces findings, and those findings inform guidance that will be applied to people exactly like her. Her exclusion has made the evidence base less applicable to her while being justified as her protection. A ten-year-old autistic boy who communicates through a picture-based system is the subject of a research study on the effectiveness of an educational intervention. Outcome data are collected from his teacher, his assistant, and his mother. Observational measures record his behaviour. At no point is he asked what he thinks. The study reports on his experience without containing it. These two cases are usually discussed in different literatures, at different conferences, by people who do not cite one another. This paper argues that they are the same case, that the mechanisms producing them are shared, and that the remedies each field has developed are complementary rather than redundant.

1.1 The shape of the argument

The paper advances four connected claims, of which the first two concern diagnosis. Exclusion in both fields arises less from principled judgement about capacity than from method inflexibility, in that the person is excluded because the instrument cannot accommodate them and the instrument's limitation is then misattributed to the person. Presumed competence, offered here as the remedy, should accordingly be understood as a methodological commitment with operational consequences rather than only as an ethical stance. The commitment is a default assumption that the person has a perspective worth eliciting, combined with an obligation to adapt method until elicitation succeeds or is demonstrably impossible, and to document the adaptation attempted.

The remaining two claims concern the remedy and the stakes. The two fields hold complementary assets, since clinical research has built rigorous architecture for capacity assessment, surrogate decision-making, and the psychometric evaluation of measures, while special education and disability studies have built rigorous practice for communication partnership, aided expression, assent and dissent recognition, and participatory research design, and neither field routinely draws on the other's work. And exclusion degrades validity, not only equity. This is the claim most likely to persuade audiences unmoved by rights arguments. A trial that excludes participants with impaired capacity produces estimates that may not generalise to the population the intervention will serve, and an educational study that relies exclusively on proxy report measures something other than what it claims to measure, since proxy and self-report diverge systematically.

1.2 Populations and scope

The paper concerns people whose participation in research is compromised by communication differences, cognitive impairment, or both. Three groups anchor the discussion: autistic children and young people with complex communication needs, adults with dementia and other progressive cognitive conditions, and people with intellectual disability across the lifespan. These groups are conventionally treated separately, and the differences between them are real, since capacity in dementia typically declines while in children it typically emerges, communication differences in autism are often lifelong and may involve no cognitive impairment at all, and intellectual disability spans a wide range of support needs. They share, however, the feature that generates the problem. In each case, the person's ability to correct a researcher's misinterpretation of them is constrained, which means the researcher's interpretation stands with unusual finality. This shared feature justifies treating them together for the purposes of methodological analysis, while requiring that specific adaptations remain population-specific.

This is a conceptual paper. It synthesises theory and evidence into a framework, advances propositions, and derives implications, and it reports no new data. Six domains are developed, each examining the problem in both fields and specifying what each can lend the other.

2. The Structure of the Shared Exclusion Problem

The first domain establishes that exclusion in the two fields is structurally similar and similarly under-examined.

2.1 Exclusion in clinical research

Exclusion of people with impaired capacity from trials operates through several mechanisms, most of them procedural rather than deliberate. Eligibility criteria frequently exclude anyone unable to provide independent informed consent, which is administratively convenient and ethically defensible on a narrow reading but removes from the evidence base precisely the population for whom many interventions are intended, a paradox displayed in its clearest form by studies of interventions for dementia that exclude people with advanced dementia. Capacity assessment thresholds compound this by being applied as global rather than task-specific judgements. Kim (2010) established that capacity is properly understood as decision-specific and variable rather than global and fixed, and a person may lack capacity to reason through complex probabilistic risk disclosure while retaining capacity to express a settled preference about participation. Global assessment collapses that distinction and excludes on the stricter standard.

Two further mechanisms operate without appearing in any protocol. Practical burden works invisibly, since a slower consent process, a need for a supporter's presence, and a requirement for adapted materials all add time in settings where recruitment operates under schedule pressure; Ford et al. (2008), reviewing barriers to recruiting underrepresented populations to cancer trials, found obstacles distributed across awareness, opportunity, and acceptance, with many operating before formal eligibility assessment. Outcome measure design excludes by proxy, because a study using a self-completed patient-reported outcome measure with dense written items has effectively excluded anyone who cannot complete it, regardless of what the eligibility criteria say.

The consequences have been examined from a rights perspective more often than from a methodological one. Iacono and Carling-Jenkins (2012) examined the human rights context for involving people with intellectual disability in medical research and argued that blanket exclusion is difficult to reconcile with equal access to the benefits of research, and McDonald and Kidney (2012) examined ethical practice in intellectual disability research and documented the tension between protection and exclusion. What neither literature has done, and what this paper attempts, is to treat the resulting gap as a defect in the evidence rather than only as an injustice to the excluded.

2.2 Exclusion in educational research

Special education research does not exclude its subjects but studies them intensively, and the exclusion therefore operates differently, through the substitution of adult accounts for the person's own. A substantial proportion of research on interventions for children with significant support needs relies on teacher report, parent report, assistant report, standardised observation, and behavioural coding. Each of these is legitimate, and collectively they produce a literature in which the subject's own perspective is largely absent.

The field's methodological literature has not registered this as a problem of the same order as its other threats to validity. Odom et al. (2005) examined methodological standards in special education research and the varieties of evidence the field draws on, and Cook and Odom (2013)

examined the relationship between evidence-based practice and implementation, but neither the standards literature nor the implementation literature has treated the absence of first-person data as a threat to validity in the way it treats, for example, inadequate blinding. The consequence is a literature that can report with confidence what an intervention did to a child's observable behaviour and with very little confidence what it did to the child.

2.3 The common mechanism

Both patterns share a mechanism worth naming precisely. In each case, a method is designed for a modal participant and therefore requires a capability, whether sustained attention to written text, verbal response to open questions, comprehension of abstract probabilistic information, or the ability to complete a Likert scale. A person lacking that capability cannot be accommodated by the method, and is then excluded or substituted. The critical move is the attribution that follows, in which the failure is assigned to the person rather than to the method, so that the person is described as unable to participate rather than the method being described as unable to accommodate. This attribution is so routine that it is rarely noticed, and it is also, in most cases, empirically wrong, because adapted methods frequently succeed where standard methods fail. Nind (2008), reviewing methodological approaches for research with people who have learning and communication disabilities, catalogued a substantial repertoire of adaptations including visual supports, simplified language, extended timeframes, familiar settings, supporter involvement, non-verbal response modes, and observational triangulation used alongside first-person elicitation rather than in place of it. The existence of that repertoire is what converts exclusion from an unavoidable limitation into a decision that could have gone otherwise.

2.4 The validity cost

The equity argument against exclusion is familiar; the validity argument deserves equal weight and receives less. External validity suffers first, since a trial that systematically excludes participants with impaired capacity produces effect estimates in a population that differs from the target population on a characteristic likely to moderate the effect. Craig et al. (2008) and Skivington et al. (2021) emphasised, in successive iterations of Medical Research Council guidance on complex interventions, that context and population interaction are central to interpreting effects rather than peripheral to them.

Construct validity suffers next. An educational study measuring quality of life, wellbeing, or engagement through proxy report is measuring the proxy's perception of those constructs, and where proxy and self-report diverge systematically, as substantial evidence across disability populations indicates they do, the study is measuring a related but distinct construct while labelling it the original. Relevance suffers last and most broadly. Pellicano et al. (2014) surveyed community views on autism research priorities in the United Kingdom and found substantial divergence between the topics the research community pursued and those the autistic community and their families regarded as important, which demonstrates that a field can be internally rigorous and collectively misdirected.

2.5 Why exclusion persists despite consensus against it

Almost no one defends blanket exclusion in principle. Guidance documents, funder statements, and disciplinary editorials routinely affirm the importance of including under-represented populations, and the practice nonetheless persists, which indicates that the causes are structural rather than attitudinal.

Four such causes are identifiable. Cost asymmetry comes first: adaptation is expensive in time, training, and materials, the costs fall on the study team, and the benefits of inclusion are diffuse and accrue to the field and to future populations, so a team under recruitment pressure and a fixed budget faces a real incentive against adaptation with no mechanism to distribute the cost. Absence of accountability comes second, since no reporting standard currently requires a study to state how many potential participants were excluded on capability grounds or what adaptation was attempted, and because the exclusion is invisible in the published record it cannot be counted, compared, or criticised. Risk framing comes third: institutional review and ethics committees are structurally oriented towards the harms of inclusion and have no corresponding mandate to weigh the harms of exclusion, so that a reviewer who approves a study that harms a vulnerable participant faces consequences while a reviewer who approves a study that excludes an entire population faces none, an asymmetry that produces conservatism which reads as caution and functions as exclusion. Skill location comes fourth, because the adaptations required are held by practitioners including communication specialists, special educators, and support staff, who are rarely involved in study design, so that the people who know how to make participation possible are not in the room when it is decided whether participation is possible. Recognising these as structural clarifies the remedy. Exhortation addresses attitude and will not shift practice, whereas changing what must be reported, who must be consulted at design, and how reviewers are mandated to weigh exclusion addresses the actual causes.

2.6 Transfer proposition one

Both fields should treat the exclusion of a person on capability grounds as a method failure requiring documentation, not as a neutral eligibility outcome. Where a person is excluded or substituted, the record should state which adaptations were attempted and why they were insufficient. This single change converts an invisible default into a visible decision subject to review.

3. Presumed Competence as a Methodological Commitment

The second domain develops the paper's central construct.

3.1 The ethical formulation and its limits

Presumed competence originated as an ethical and educational stance, and its content is that in conditions of uncertainty about a person's understanding or capability, the assumption most likely to produce good outcomes and least likely to produce harm is the assumption of competence. The argument's structure is asymmetric risk. If competence is presumed and the person lacks it, the cost is wasted effort and possibly some frustration. If incompetence is presumed and the person possesses it, the cost is that a capable person is systematically denied access, opportunity, and voice, often for years and sometimes permanently. The asymmetry favours presumption of competence. As an ethical stance this is sound and widely endorsed. As a guide to research practice it is insufficient, because it specifies an attitude without specifying an operation, and a researcher can sincerely presume competence and still design a study that cannot accommodate the person. What follows attempts to supply the missing operation.

3.2 The methodological reformulation and the double empathy correction

The paper proposes reformulating presumed competence as a three-part methodological commitment. The first part is a default assumption that the person has a perspective relevant to the research question and that the perspective is elicitable in principle. The second is an adaptation

obligation, under which the researcher must adapt method until elicitation succeeds or until adaptation has been exhausted, so that standard method failure triggers adaptation rather than exclusion. The third is a documentation requirement, under which adaptations attempted, their outcomes, and the basis for any eventual conclusion of non-elicitability are recorded as study data rather than as administrative notes. The third part converts the first two from aspiration into practice, because it creates a record against which the adaptation obligation can be assessed.

Milton (2012) articulated the double empathy problem, proposing that difficulty in communication between autistic and non-autistic people is reciprocal rather than located in a deficit on one side, and the proposal has substantial methodological implications beyond its original context. If communication breakdown is mutual, then a researcher's failure to elicit a response is evidence about the interaction and not only about the participant. The appropriate inference is that the method has not yet matched the person, which prompts continued adaptation, and the inappropriate but standard inference is that the person cannot respond, which terminates the attempt.

The same logic extends beyond autism to dementia and intellectual disability research. A person who does not answer an abstract question may answer a concrete one, a person who cannot rate a scale may indicate a preference between two tangible options, and a person who becomes confused in an unfamiliar clinic may be lucid at home. In each case the observation that licenses exclusion under the standard inference licenses a further attempt under the reformulated commitment, and the difference between the two is not a difference in charity but in what the researcher takes the failure to be evidence of.

3.3 The complementary contributions of the two fields

Clinical research brings analytic precision that disability studies often lacks. Kim's (2010) framework distinguishes the abilities involved in decisional capacity, including understanding, appreciation, reasoning, and expression of a choice, which permits a granular judgement in which a person may retain some components and not others and a study may be designed to require only the components retained. Research ethics frameworks add structured proportionality, calibrating protective requirements to risk; Emanuel et al. (2000) identified independent review, favourable risk-benefit ratio, and respect for participants as distinct requirements, and a minimal-risk observational study and a first-in-human trial warrant different capacity thresholds, with the framework supporting an articulation of why. The field also brings psychometric discipline, having developed rigorous standards for evaluating whether a measure actually measures what it claims. Prinsen et al. (2018) set out guidance for systematic review of patient-reported outcome measures, and this machinery, applied to adapted measures, permits the question of whether an adaptation preserves validity to be answered empirically rather than asserted. This matters directly for the argument of this paper, since the case for adaptation is weakened rather than strengthened if adaptation is exempted from the standards applied to everything else. Special education and disability studies bring the practical repertoire that clinical research lacks. Adaptation is routine rather than exceptional in these fields, which have extensive practice in modifying materials, simplifying language, adding visual supports, and restructuring tasks as daily work. Mesibov et al. (2005) described the use of physical organisation, visual schedules, work systems, and task structure to make expectations explicit and reduce reliance on verbal prompting, and the underlying principle that the environment can carry part of the comprehension burden applies directly to research encounters. Non-verbal response modes including picture selection, object choice, gesture, and behavioural indication are treated as legitimate response modalities rather than as failures to respond. And Walmsley and Johnson (2003) documented approaches to inclusive

research with people with learning disabilities in which participants hold roles beyond that of data source.

3.4 Transfer proposition two

Clinical research should adopt special education's adaptation repertoire as a standard component of protocol design for studies involving populations with communication or cognitive difference, rather than treating adaptation as an exceptional accommodation. Special education should adopt clinical research's psychometric discipline, testing empirically whether its adaptations preserve the validity of what is measured.

4. Consent and Assent as Continuous Processes

The third domain addresses authorisation, which both fields treat as an event and both should treat as a process.

4.1 The event model and its failure

Regulatory architecture treats consent as an event with a document as its trace, while ethical scholarship has long insisted that it is a process. Grady (2015) catalogued enduring challenges including comprehension deficits, therapeutic misconception, lengthy legalistic forms, and the difficulty of consent under impaired capacity. The Declaration of Helsinki requires adequate information, comprehension, and voluntariness, none of which is guaranteed by a signature (World Medical Association, 2013), and Beauchamp and Childress (2019) situate respect for autonomy alongside beneficence, non-maleficence, and justice, a framing that makes clear why a formally valid but substantively hollow consent satisfies no one.

Three strains break the event model in the populations under discussion. Capacity fluctuates in dementia and in delirium-prone hospitalised populations, where it is neither binary nor stable, so that a single assessment at a single moment cannot govern participation extending over months. Capacity emerges in children, where parental consent with child assent is the standard arrangement but assent is frequently treated as a formality rather than as a substantive requirement with its own elicitation challenges. And dissent is frequently expressed outside the terms the consent form specifies, since a person may be unable to articulate withdrawal in those terms while communicating unwillingness unmistakably through behaviour, posture, or withdrawal of engagement. The event model has no place to record this, which means that the clearest available evidence of a participant's wishes is the evidence the architecture is least able to receive.

4.2 Process consent and supported decision-making

Dewing (2007) developed a process consent method for research with people who have dementia, emphasising repeated, embodied, context-sensitive re-establishment of willingness rather than a single authorising act. The method involves establishing the person's baseline state, re-establishing willingness at each contact, monitoring for indicators of discomfort or reluctance, and treating those indicators as authoritative. The approach travels well across populations, and its core insight is that willingness is a present-tense state which must be checked in the present tense, and that the checking can rely on behavioural and relational indicators where verbal confirmation is unavailable. Special education's practice in assent and dissent recognition is directly relevant here and is rarely cited in clinical contexts. Practitioners working with students who have complex communication needs develop fine-grained reading of engagement, refusal, tolerance, and distress, which is precisely the skill process consent requires and which exists as trained practice in one field and as improvisation in the other.

The Convention on the Rights of Persons with Disabilities articulates a related shift from substituted to supported decision-making, framing support as the mechanism by which legal capacity is exercised rather than as an alternative to it (United Nations, 2006). The distinction has practical content, since substituted decision-making asks what the surrogate judges to be in the person's interest or what the person would have wanted, while supported decision-making asks what the person wants, with whatever assistance is required for them to form and express that preference. The second is harder and produces better information, requiring time, familiarity, adapted materials, and a supporter who understands the difference between assisting expression and supplying content. That last distinction connects directly to the scaffolding discipline developed in the literature on frontline support, where the supporter's task is the least assistance that permits the person's own preference to emerge rather than the most assistance that produces an answer.

4.3 Advance planning and longitudinal consent documentation

Advance care planning offers a bridging construct between the two fields that neither has exploited. Sudore et al. (2017) developed a consensus definition framing advance care planning as a process supporting adults in understanding and sharing their values, goals, and preferences regarding future medical care, and emphasising that it is ongoing rather than documentary. The structural parallel to the individualised education plan is close, since both are forward-looking instruments intended to encode a person's needs and preferences for use in future decisions, and both are prone to the same failure of becoming documents rather than remaining processes.

The parallel generates a mutual lesson. Advance care planning practice has developed sophisticated approaches to eliciting values from people whose capacity is declining, which educational planning could adopt for students approaching transition to adulthood, while educational planning has developed structured review cycles with defined participation, which advance care planning often lacks. What both point towards is a record of authorisation that extends over time, and the paper proposes longitudinal consent documentation as a standard study record. Such a record would capture not only initial authorisation but subsequent re-confirmations, observed indicators of ongoing willingness, moments at which comprehension was re-checked, adaptations made to accommodate fluctuating capacity, and any behavioural dissent observed together with how it was responded to. It would serve three functions: protecting participants by making ongoing willingness auditable, protecting frontline staff by making their judgement visible and reviewable rather than private, and improving science by allowing analysts to understand the conditions under which data were provided.

4.4 Transfer proposition three

Both fields should replace the consent event with a documented consent process. Clinical research should adopt special education's trained practice in assent and dissent recognition and should require, in protocols involving populations with fluctuating or emerging capacity, an explicit account of how ongoing willingness will be re-established. Special education should adopt clinical research's requirement that authorisation for research participation be formally recorded and independently reviewable, which is frequently weaker in educational settings than in clinical ones.

5. Partner-Dependent Expression and the Validity of the Record

The fourth domain concerns what happens between a person's intention and the record of it.

5.1 The partner as part of the instrument

For a person with complex communication needs, the adult present when a communicative attempt occurs determines whether that attempt becomes communication or dissipates, which makes the partner a constitutive element of the communication system rather than a facilitator of it. Augmentative and alternative communication encompasses aided and unaided systems including picture exchange, communication boards, and speech-generating devices (Beukelman & Light, 2020). The Picture Exchange Communication System was designed to establish initiation rather than responsive labelling, teaching the learner to approach a partner and exchange a symbol (Bondy & Frost, 1994), and Ganz et al. (2012) synthesised single-case research on aided systems for individuals with autism and found generally positive effects across communication outcomes. Light and McNaughton (2014) reframed the objective as communicative competence, comprising linguistic, operational, social, and strategic components, and argued that competence is achieved in interaction rather than possessed by an individual. The implication for research is direct and largely unrecognised, which is that the partner's competence forms part of the measurement instrument. A study that reports what a participant expressed without characterising who supported the expression and how has described half of the apparatus that produced its data.

5.2 Partner behaviours and the interviewer analogue

Four partner behaviours are decisive, and each has a research analogue. Wait time comes first, since symbol selection is slower than speech, sometimes substantially, and adults consistently underestimate the pause required and fill it, so that every filled pause removes a communicative turn; in research encounters the same dynamic governs interviews with participants who process slowly, including many people with dementia. Modality acceptance comes second, because a person communicating through a board, gesture, vocalisation, or body orientation is communicating, and treating only the formal system as legitimate narrows the channel, the research analogue being whether non-standard response modes are recorded as data or as missing data. Modelling without demanding comes third, since aided language modelling builds receptive understanding without converting every exchange into a test, and the research analogue is whether the encounter is framed as assessment or as conversation, which materially affects what is expressed. Presumption of intent comes fourth, because a partner who attributes a failed exchange to the person's impairment stops adjusting while a partner who treats the breakdown as mutual keeps searching, which is the double empathy correction operationalised at the level of a single interaction. Clinical research has an established literature on interviewer effects, social desirability, and acquiescence bias, but treats these as sources of measurement error to be minimised rather than as a constitutive feature of certain encounters. For participants with cognitive impairment the distinction between interviewer effect and enabling condition collapses, since the same adaptations that introduce interviewer influence, including rephrasing, prompting, concretising, and offering candidate responses, are also the adaptations without which no response is obtained. The field's framework of minimising influence provides no guidance here, because minimising influence to zero means obtaining nothing. What is needed is a calibration framework, and this is exactly what the augmentative communication literature supplies in the form of a principled account of the least partner input that permits authentic expression. Braun and Clarke (2006) and Nowell et al. (2017) addressed rigour in thematic analysis and Lincoln and Guba (1985) established trustworthiness

criteria including credibility, dependability, confirmability, and transferability, but all of these apply downstream of collection and cannot repair distortion introduced within it.

5.3 Documenting conditions of expression and training the partner

The proposal that follows is that studies involving participants with communication differences should document the conditions of expression alongside the data expressed, recording which system was used, who the partner was, what wait time was allowed, which prompts were provided, which modalities were accepted, and where the participant's meaning was inferred rather than directly expressed. This is analogous to reporting an assay's laboratory conditions. Data produced under materially different conditions of expression are not straightforwardly comparable, and at present the conditions are neither recorded nor considered.

A further implication follows for both fields. If expression is partner-dependent, then partner behaviour is a legitimate target of intervention and a legitimate source of variance. In education this means that coaching directed at the communication partner may produce learner gains independent of learner-directed intervention, and that studies attributing outcomes to a communication system without characterising partner behaviour carry an unmeasured confound. In clinical research it means that interviewer and coordinator training in partner behaviours is a data quality intervention rather than a courtesy, and that inter-interviewer variation in populations with communication differences may be substantially larger than standard reliability assumptions allow. Neither field currently collects the information that would establish how large that variation is, which is itself a consequence of treating the partner as external to the instrument.

5.4 Transfer proposition four

Both fields should treat the communication partner as part of the measurement instrument, should train partner behaviour explicitly, and should document conditions of expression as study metadata. Clinical research should import the augmentative communication literature's calibration framework to replace its unusable ideal of minimised interviewer influence in populations where influence is the enabling condition of response.

6. Proxy Report, Observation and Outcomes That Matter

The fifth domain concerns measurement: what is measured, by whom, and whether it corresponds to what matters.

6.1 The proxy problem

Proxy report is ubiquitous in both fields and is frequently necessary. It is also systematically biased in a known direction, and the bias is under-acknowledged. Proxies tend to report observable domains more accurately than internal ones, so that physical function, activity participation, and behaviour are reported with reasonable correspondence while pain, mood, anxiety, satisfaction, and quality of life are reported with substantially poorer correspondence, and the divergence is not random, since proxies with greater caregiving burden and greater emotional investment tend to report differently from those with less. The methodological consequence is specific. For internal constructs, proxy report does not approximate self-report with added error but measures a different construct, namely the proxy's perception, which is influenced by the proxy's own state. Labelling this as the person's quality of life is a construct validity failure rather than a precision problem, and the distinction matters because precision problems are addressed by larger samples while construct validity failures are not addressed by anything except measuring something else.

Neither field routinely reports proxy-self divergence, routinely selects measures on the basis of demonstrated proxy validity for the specific construct, or routinely frames proxy data as what it is. The result is a literature in which a substantial proportion of reported outcomes for these populations describe how those populations appear to the adults around them, presented as descriptions of the populations themselves.

6.2 Observational measurement and its limits

Where proxy report is unavailable or inappropriate, both fields turn to observation, and behavioural coding, engagement measures, and structured observation schedules produce reliable data about what a person does. Observation nonetheless carries a specific interpretive risk, since it records behaviour and licenses inference about internal states, and the inference is made by the observer. A student who is quiet and on task is coded as engaged, and a person with dementia who is calm is coded as comfortable, when in both cases the behaviour is compatible with the inferred state and with several others including compliance, resignation, withdrawal, and sedation.

Dunn's (1997) model relating sensory processing patterns to behavioural responses illustrates why the inference is particularly hazardous in autistic populations, since the same observable behaviour can arise from opposite internal states depending on threshold and response pattern. An observer without access to the person's own account has no principled way to distinguish the two, and the coding scheme will not reveal the ambiguity because the scheme was built on the assumption that the behaviour indicates the state. Observation is therefore strongest as triangulation with first-person data and weakest as substitution for it, which is the reverse of how it is typically used. The recommendation that follows is not to abandon observational measurement but to stop treating it as the fallback that makes first-person elicitation unnecessary.

6.3 Outcomes that matter and the capabilities frame

A prior question precedes measurement selection, which is whether the outcome measured is the outcome that matters to the person. Williamson et al. (2017) documented the core outcome set movement, which seeks to establish agreed minimum outcomes for research in a condition area with stakeholder involvement in defining them, and Prinsen et al. (2018) set out standards for evaluating patient-reported outcome measures. Both represent substantial methodological infrastructure for which special education research has no equivalent.

The gap matters because educational research outcome selection is frequently driven by what is measurable and administratively required rather than by what stakeholders regard as important. Goal attainment against individualised plan objectives is the field's characteristic outcome, and it inherits whatever priorities the plan encoded, which were set by professionals. Pellicano et al. (2014) demonstrated divergence between research community and autistic community priorities, and Fletcher-Watson et al. (2019) argued for participatory approaches to autism research that shape questions as well as methods, with both pointing towards the same correction: outcome selection is a site where the person's perspective should enter, and currently rarely does.

Nussbaum (2011) developed the capabilities approach as a framework evaluating arrangements by the substantive freedoms they make available to a person rather than by resources provided or procedures followed, and the frame is useful in both fields because it reorients outcome selection. The question becomes not whether a service was delivered or a behaviour changed but whether the person's actual range of possible doings and beings expanded, which is closer to what families, participants, and practitioners describe as mattering and further from what current measurement captures. Applied to clinical research in serious illness it directs attention towards whether a person

retained the capacity to participate in decisions, maintain relationships, and act on their own values, and applied to special education it directs attention towards whether a student's communicative, social, and self-determining capabilities expanded rather than whether a behavioural target was met.

6.4 Goal attainment as a bridging method

One measurement approach deserves specific attention because it already exists in both fields under different names and could be developed jointly. Educational practice measures progress against individualised objectives written into a student's plan, while rehabilitation and some areas of health research use goal attainment scaling, in which individually negotiated goals are defined in advance with specified levels of achievement, permitting individualised targets to be aggregated across participants in a standardised metric. The approach has a property that standardised measures lack, since it permits the outcome to be specific to the person while remaining analysable at group level, which is a substantial advantage for populations whose situations vary widely and for whom no single standardised instrument is appropriate. It also has a characteristic weakness that both fields have encountered, which is that goal quality determines everything. Goals set by professionals without the person's involvement measure professional priorities, goals set at an achievable level produce attainment that reflects target-setting rather than change, and goals described in terms that cannot be reliably rated produce unreliable data. The method is therefore only as good as the process that generates the goals, and that process is exactly where the person's perspective is most often absent. The two fields have developed partial solutions to these weaknesses and have not exchanged them. Educational practice has extensive experience in writing observable, measurable objectives and in structured review cycles, while health research has developed more rigorous approaches to blinding goal rating from the person who set the goal and to establishing inter-rater reliability on attainment judgements. A jointly developed methodology would combine educational practice in goal specification and review with health research discipline in rating and reliability, and would incorporate the person's own involvement in goal-setting as a requirement rather than an aspiration. The result would address the field's most persistent measurement problem, which is how to capture outcomes that genuinely matter to individuals whose situations are too heterogeneous for standardised instruments to serve.

6.5 Transfer proposition five

Both fields should require explicit justification of measurement source, stating for each outcome whether self-report, proxy report, or observation was used and why, together with available evidence on proxy validity for that specific construct. Special education should develop core outcome sets with stakeholder involvement, on the model established in health research. Clinical research should adopt goal attainment methodology from educational and rehabilitation practice for outcomes that are irreducibly individual.

7. Participatory Design and the Redistribution of Research Authority

7.1 The ladder of involvement

Involvement of the people a study concerns spans a range of depth, and the range is frequently collapsed in reporting. At the shallowest level involvement is consultative, in that people are asked to comment on materials already designed. At an intermediate level it is collaborative, in that people participate in decisions about design, conduct, and interpretation. At the deepest level it is

controlled, in that people set the agenda and lead the work. Reporting that describes all three as involvement makes the quality of any particular instance unassessable.

Brett et al. (2014) mapped the impact of patient and public involvement across health and social care research and found effects on relevance, recruitment, materials, and dissemination, and Staniszewska et al. (2017) developed the GRIPP2 reporting checklists to address exactly the problem of involvement being claimed without being described. Walmsley and Johnson (2003) documented inclusive research traditions in intellectual disability where people with learning disabilities hold roles as advisers, co-researchers, and leads, and Fletcher-Watson et al. (2019) made the case for participatory autism research shaped by autistic people's priorities.

7.2 The specific difficulty in these populations

Participatory approaches face a difficulty in populations with significant communication and cognitive differences that the general involvement literature does not address. Standard involvement mechanisms are meeting-based, document-based, and discussion-based, so that an advisory group meeting with papers circulated in advance excludes precisely the people whose exclusion the mechanism was designed to remedy. The result is a familiar substitution in which the group consists of family members, advocates, and people with milder impairment, and is reported as involvement of the population. This is not a criticism of those participants; whose contributions are valuable. It is an observation that the mechanism reproduces at the involvement stage the same exclusion it was created to correct, and that the reproduction is invisible for the same reason it is invisible elsewhere, namely that no record distinguishes who was in the room from who the room was meant to represent. The remedy requires importing the adaptation repertoire from the earlier domains into involvement practice itself, including visual materials, individual rather than group formats, familiar settings, extended timeframes, communication partners, and non-verbal response modes. Nind (2008) catalogued methods that apply as readily to involvement as to data collection, which means that the field already possesses what involvement practice needs and has simply not applied it at this stage of the process.

7.3 Agenda-setting and what each field brings

Of all the stages at which involvement can occur, agenda-setting has the greatest effect on whether research serves the people it concerns, and it is the stage at which involvement is rarest. Pellicano et al. (2014) demonstrated the consequence in autism research, finding sustained investment in areas the community regarded as lower priority alongside under-investment in areas regarded as urgent, and the pattern is not unique to autism. Research agendas are shaped by funding structures, disciplinary incentives, publication norms, and researcher interest, all of which operate independently of the priorities of affected populations, and involvement at design, conduct, or dissemination cannot correct an agenda set without the population. A perfectly executed study of the wrong question remains a study of the wrong question. Clinical research brings established infrastructure to this problem, including funder requirements for involvement, reporting standards through GRIPP2, and organisational structures such as patient advisory groups with defined roles and remuneration. These are imperfect but real, and special education research has no comparable infrastructure. Special education and disability studies bring the practice and the theoretical commitment, including inclusive research traditions with decades of development, sophisticated adaptation repertoires, and a disability rights framework grounded in the principle that decisions about a group should involve that group. The Convention on the Rights of Persons with Disabilities encodes this commitment (United Nations, 2006), and Bronfenbrenner's (1979) ecological model

provides the theoretical account of why decisions made at distant system levels shape proximal experience. The exchange available here is therefore infrastructure in one direction and practice in the other, which is the same complementarity the paper has identified in every preceding domain.

7.4 Transfer proposition six

Both fields should extend involvement to agenda-setting and should adapt involvement mechanisms using the same repertoire applied to data collection, so that involvement does not reproduce the exclusion it exists to remedy. Special education research should adopt formal involvement infrastructure and reporting standards from health research. Clinical research should adopt inclusive research traditions from disability studies, in which affected people hold roles beyond advisory.

8. Conclusion

This paper has argued that clinical research and special education share an exclusion problem, that the problem is methodological before it is ethical, and that each field holds remedies the other lacks. The mechanism is the same in both. An instrument is designed for a modal participant and therefore presupposes a capability, whether sustained attention to written text, verbal response to open questions, comprehension of probabilistic information, or the completion of a rating scale. A person lacking that capability is excluded in clinical research or substituted by an adult proxy in educational research, and the limitation is attributed to the person rather than to the method. The attribution is usually wrong, since adapted methods frequently succeed, and it is self-reinforcing, because people who are never included generate no evidence that they could have been, and instruments validated only on the samples they admit remain silent on the populations they exclude. Six domains were developed on that basis: the structure of the shared exclusion problem, presumed competence as a methodological commitment, consent and assent as continuous processes, partner-dependent expression, proxy report and outcomes that matter, and participatory design. Presumed competence, reformulated as a methodological commitment rather than only a moral posture, provides an operational alternative. It is not a claim about anyone's ability. It is a default and a burden of proof; the default is that the person has a perspective worth eliciting, and the burden falls on the method, which must be adapted until elicitation succeeds or until its failure is demonstrated and recorded. So construed, the question of whether a person can participate becomes a property of the pairing of person and method rather than of the person, which makes it provisional, testable, and reviewable. The commitment does not guarantee that everyone can be included on every question. It guarantees that exclusion becomes a documented decision rather than an invisible default, and this is what the paper's central transfer proposition asks of both fields. The remaining propositions follow the same logic of exchange. Clinical research should adopt special education's adaptation repertoire, its trained practice in assent and dissent recognition, its calibration framework for communication partnership, and its goal attainment methodology. Special education should adopt clinical research's psychometric discipline, its requirement that authorisation be formally recorded and independently reviewable, its core outcome set methodology, and its formal involvement infrastructure. The implications are tractable and fall on identifiable actors. Protocols should specify adaptation in advance rather than treating it as reactive accommodation, and exclusion on capability grounds should require documented justification. Ethical review can ask how ongoing willingness will be re-established and how dissent will be recognised, both of which document review cannot otherwise detect. Measurement source should be justified for each outcome with proxy validity evidence for the specific construct, and

conditions of expression should be recorded as study metadata wherever a participant relies on augmentative communication or substantial interviewer support. Measure developers hold the highest-leverage position of all, since instruments determine who can be studied with them, and reporting the capabilities an instrument presupposes would remove much of the exclusion described here. The argument carries real limits. It is conceptual and reports no new data. Adaptation is not neutral, since simplified language, closed formats, and supported response can introduce acquiescence and suggestibility and can compromise comparability, which is precisely why adaptation without psychometric evaluation would substitute one validity problem for another. Where expression depends on a partner the record is jointly produced, and the authorship question this raises requires faded and documented support, reporting of the support condition, and caution about the weight placed on responses obtained under maximal support. Inclusion also imposes burden on people who may fatigue quickly, so the trade-off must be made deliberately and burden measured as an outcome rather than assumed away.

Both fields understand themselves as serving people who cannot fully advocate for themselves, and both have built protective structures on that understanding. Protection is a legitimate obligation. But protection that operates by removing people from the evidence that governs them has an unexamined cost, and the cost falls on the protected. The woman excluded from the symptom management trial will still receive symptom management, delivered according to findings produced without her. The boy whose outcomes were reported by three adults will still be taught according to what those reports showed. Neither was protected from the intervention. Each was protected only from the opportunity to influence it. The alternative is not to abandon protection. It is to recognise that the harder work of adaptation is what protection actually requires, and that a field which excludes because adaptation is difficult has chosen its own convenience and named it safety.

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